

**Schizophrenia in adults with intellectual disability and  
autism: behavioural indicators and examination of staff  
communication skills**

**by**

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**Oslo 2009**

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*Series of dissertations submitted to the  
Faculty of Medicine, University of Oslo  
No. 923*

ISBN 978-82-8072-928-6

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# 1. OVERVIEW

## 1.1 Summary

Psychiatric illness in patients with moderate, severe, and profound intellectual disability has not been attended to adequately. These patients have traditionally “fallen in between” the general psychiatric services and the specialised services for people with intellectual disability.

Patients with moderate, severe, and profound intellectual disability and autism cannot report their symptoms when they experience a psychotic condition. Assessments and treatment regimens must be based upon thorough observations of behaviour characteristics. There is a need to establish behavioural indicators, which relate to both case identification and treatment. Case identification and suitable treatment practices are sparsely studied. The main topic in this thesis is to explore whether behavioural indicators of schizophrenia in adults with moderate, severe, and profound intellectual disability and autism can be used for both case identification and selection of appropriate treatment strategies.

Behavioural disorganisation was found to be a reliable and valid indicator of schizophrenia in patients participating in this project. Behavioural disorganisation and speech disorganisation was for the most part found to occur concurrently.

Behavioural disorganisation was found to be a suitable effect measure for valid evaluation of staff communication skills. Four selected categories of staff communication skills - *responsiveness*, *joint attention*, *task sustenance*, and *emotional support* - when taken together, were effective in improving behavioural disorganisation and the amount of patient initiatives. *Task sustenance* and *joint attention* was most effective in decreasing disorganised behaviour, whereas *meaningful response* was most effective in increasing initiatives from the patient.

Further research is needed to examine the validity of the findings in other samples of staff and patients.

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### ***1.3 List of papers***

Paper I:

Bakken, T.L., Friis, S., Lovoll, S., Smeby, N.A., Martinsen, H. (2007) Behavioral disorganisation as an indicator of psychosis in adults with intellectual disability and autism. *Mental Health Aspects of Developmental Disabilities*, 10:2, 37-46.

Paper II:

Bakken, T.L., Eilertsen, D.E., Smeby, N.A., Martinsen, H. (2008) Observing communication skills in staffs interacting with adults suffering from intellectual disability, autism and schizophrenia. *Nordic Journal of Nursing Research and Clinical Studies*, 28:1, 30-35.

Paper III:

Bakken, T.L., Eilertsen, D.E., Smeby, N.A., Martinsen, H. (2008) Effective communication related to psychotic disorganised behaviour in adults with intellectual disability and autism. *Nordic Journal of Nursing Research and Clinical Studies*, 88:28, 9-13.

Paper IV:

Bakken, T.L., Eilertsen, D.E., Smeby, N.A., Martinsen, H. (2009) The validity of disorganised behaviour as an indicator of psychosis in adults with autism and intellectual disability: a single case study. *Mental Health Aspects of Developmental Disabilities*, 12:1, 17-22.

## ***1.4 Acknowledgements***

This thesis is based on research initiated by a project supported by the National Norwegian Autism Unit at the Oslo University Hospital, Rikshospitalet. The main aim of the project has been to implement psychiatric services to patients who previously not have been provided such services.

The present study on schizophrenia in adults with intellectual disability and autism would not have been possible without the cooperation of patients, their families and colleagues at the Psychiatric Department for patients with intellectual disability at the Oslo University Hospital, Ullevaal. I especially want to thank psychiatrist Sverre Løvøll for inspiring discussions over the last decade about the understanding of mental illness in intellectually disabled patients. I also want to thank nurse aid Margit Reinertsen and the other milieu therapists at Slottet I for initially showing me how psychiatric milieu therapy can be provided to patients who cannot speak. They inspired me to initiate the staff communication study.

Because the topic in this thesis had not previously been examined frequently, it was essential to get supervision from researchers, possessing knowledge on intellectual disability and autism, and schizophrenia, respectively. I am most thankful for supervision and support from my counsellors: Harald Martinsen, professor of special need education at University of Oslo; professor dr. med. Svein Friis at the Oslo University Hospital, Ullevaal, and Nina Aarhus Smeby, RN, Ph.D., at the Oslo University Hospital, Ullevaal. I will also thank psychologist and senior IT engineer Dag Erik Eilertsen for methodological and statistical support.

I also want to thank my colleges in the autism and psychiatry project for their feedback: Gro Kalvenes, Jarle Eknes, Nils Egil Foss and Sissel B. Helverschou. Our librarian, Eldbjørg Eien, has provided me with articles and books and conversations. Thank you!

Finally I want to thank the “home department” - Arne and my sons Johan and Henrik for their understanding and social support during the last years.



### ***1.5 List of abbreviations***

ID:	Intellectual disability
BD:	Behavioural disorganisation
ICD 10:	International Classification of Diseases, Tenth edition
DSM IV:	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
ASD:	Autism Spectrum Disorders
PAC:	Psychopathology in Autism Checklist

### ***1.6 Terms, concepts and diagnostic criteria***

The use of the concept **phenomenology** in this thesis is linked to the appearance of symptoms. The Greek origin of the concept is *phenomenon*, which means “manifestation” or “what is appearing”. The philosophical meaning is commonly linked to empirical studies of objects or situations or manifestations of an abstract phenomenon like for example friendship. In health science, the concept has been closely linked to the individual life experiences (Merleau-Ponty, 1962; Omery, 1983). In the caring sciences, phenomenology is for the most part linked to a method of research where the patient’s experience is the basis of knowledge (Omery, 1983).

The diagnostic term for **intellectual disability** (ID) is still *mental retardation* (DSM-IV and ICD-10), but this term is now infrequently used in clinical practice and research. The terms *intellectual disability* and *learning disability* are the currently used terms. As learning disability is a broader term that includes different learning difficulties, also found in the normal intelligent population, I have chosen to use the term *intellectual disability*.

The diagnostic category **schizophrenia** has not been recommended when the patient does not have the ability to report on core symptoms - mainly delusions and hallucinations (Lund, 1985; Reid, 1972b, 1989). A possible approach is therefore to use the term *schizophrenia-like psychosis* (Sverd et al, 1993), a term which will maintain the intension of keeping disorders in the schizophrenia spectrum (non-affective psychoses) apart from affective psychoses. The ICD-10-originated manual *Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disability*, DC-LD, has gathered all diagnoses within the schizophrenia spectrum under the sub heading *non-affective psychosis* (Royal College of Psychiatrists, 2001). The term schizophrenia-like has been used in paper I of this

thesis. In the rest of this thesis I have chosen to use the term schizophrenia as synonymous for schizophrenia-like psychosis and non-affective psychosis.

The term **autism** was first launched by the German-American child psychiatrist Leo Kanner (Kanner, 1943). Kanner thought that the children he described in his paper suffered from a rare variant of childhood schizophrenia, which he named *autism*, a term from Eugene Bleuler (Andreasen and Akisal, 1983). The term *Autism* (from Greek *auto* = self) refers to the schizophrenic symptom of extreme social withdrawnness. This term has since followed individuals with autism, though the condition long ago has been differentiated from the schizophrenia spectrum (Kanner, 1971; Fish and Rivto, 1979). Core symptoms of schizophrenia, delusions, and hallucinations were found to be absent in people with autism (Rumsey et al, 1985). The origin of the term has caused confusions, both in clinical practice and in research (ibid). The diagnosis of Infantile Autism was included for the first time in the DSM – III in 1980 (Overall and Campbell, 1988).

The term “**effective communication**” relates to staff-patient communication. In this thesis the term “effective communication” is defined as staff communicative acts *commonly assumed to decrease the patient’s symptoms when experiencing an episode of schizophrenia*. “Effective communication” is consequently a theoretical term that includes strategies meant to facilitate the interaction process between patients and staff. “Effective communication” refers to communicative skills recommended in the research literature and encompasses communication between professionals and patients with intellectual disability, autism and schizophrenia. To be able to communicate effectively, it is presumed that the staff must know the patient well enough to assess what is meaningful in the communication process. This entails knowing the patients’ communicative style including idiosyncratic phrases and gestures, for instance when the patient is hammering on the kitchen door and at the same time touching his mouth, this means he is thirsty. The term “effective communication” was defined prior to the empirical investigation of staff communication. Whether these communicational strategies are truly “effective” is thus an empirical question, which is investigated and discussed in papers presented in this thesis.

**Learning disability nursing** is a term used mainly in United Kingdom (Turnbull, 2004). It is a branch of nursing, although the learning disability nurses did not receive their

training in fundamental nursing at the same time as general nurses before 2000 (ibid.). The learning disability nurses in the UK seem to have been a marginalised group of caregivers who have not been able to profit from models developed in the general nursing field (Thompson and Pickering, 2004; Turnbull, 2004; Duff, 1997).

In Norway the ‘social caregivers’ (In Norwegian *vernepleiere*) – for more than 50 years - have cared for people with ID. In Demark there is another educational system for clinicians who care for intellectually disabled patients – ‘social pedagogues’. In Sweden there is no unique educational system for caregivers for people with ID. It seems at this point impossible to give a clear definition of ‘learning disability nursing’ – because the task of caring for people with ID seems to differ from one country to another – both in naming the discipline and in content of practice. In this thesis learning disability nursing will be used synonymously with the Norwegian term *vernepleie*.

## **Diagnostic criteria**

Up to 1993/ 1994 a patient could not, according to DSM-III and IDC-9, receive co-morbid autism and schizophrenia diagnoses. This view on co-morbidity reflects the current opinion about autism in the 1950s and 1960s, that autism was a subgroup of the psychoses (Fish and Rivto, 1979). As the knowledge about autism expanded, it came to include the understanding of co-morbid psychiatric conditions to autism, and the manuals ICD – 10 and DSM – IV allowed co-morbid autism and schizophrenia (World Health Organization, 1993 and American Psychiatric Association, 1994).

In addition to the global functioning criteria, the ICD-10 diagnoses within the schizophrenia- spectrum depend on self-report skills in the patients (World Health Organization, 1993).

The DSM-IV pays more attention to observable symptoms than ICD-10. The present work therefore refers to the DSM-IV criteria.

## ***1.7 Comments on the thesis content***

This thesis presents a project intended to shed light on the difficulties meeting professionals that work with identification of schizophrenia in people with very limited verbal language, and who are intellectually disabled and have autism. The thesis will provide information, analyses and discussions supplementary to the four papers in this project,

The *introduction* provides information about schizophrenia in adults with ID and autism and about current knowledge in this specific field of research. Major difficulties in the identification process caused by the patient's lack of verbal language, overlapping and atypical symptoms, and diagnostic overshadowing, are discussed. Because of the dearth of research papers and measures on both diagnostic criteria and staff communication related to the target group, the design in this project included new, formerly un-investigated measures. The *method section* therefore includes an introduction to these new measures as well as additional information and analyses not included in the published papers. Discussions and information concerning methodological questions, such as the small sample sizes, choice of analytical strategies, reliability of measures, and validity of the study conclusions are included in the method section. Some additional results from new analyses are presented in the synopsis with additional results-section. The *discussion section* encompasses discussion of the three main research questions, as well as a discussion of strengths and limitations. In the *conclusions section* the main findings and conclusions from all papers are summarized, as well as clinical implications of the main findings. References used in the thesis are listed alphabetically at the end.

## 2. INTRODUCTION

### *2.1 Schizophrenia in adults with intellectual disability and autism*

When planning this thesis, knowledge of schizophrenia in the more severely intellectually disabled individuals was very limited. Now, in 2009, it still is. It has earlier been assumed that schizophrenia could not occur in individuals with an IQ lower than approximately 50, who cannot report on core features of the disorder (Lund, 1985; Reid, 1972a; 1972b). It has also been claimed that psychotic disorders cannot be diagnosed in 'idiots' (Reid, 1972a). Nevertheless, schizophrenia in intellectually disabled individuals has been described already in the late 19<sup>th</sup> century (Reid, 1972a). Most of the knowledge about schizophrenia and other psychotic disorders in intellectually disabled individuals is from studies involving patients with mild ID (ibid.). There is a dearth of studies on how symptoms in the more severely intellectually disabled patients manifest.

More recent research has revealed that individuals with ID at all levels, even individuals with profound ID who do not communicate verbally, are at a higher risk for developing psychiatric problems than people within the normal IQ range (Deb et al, 2001; Smiley et al, 2007). It is suggested that people with both ID and autism are even more vulnerable to mental health problems, than people with ID only (Bradley et al., 2004; Brereton, Tonge, and Einfeld, 2006; Morgan et al., 2003; Mouridsen et al., 2008).

Few studies examined phenomenology, i.e., what kind of symptoms a patient with ID and autism displays, while experiencing an episode of schizophrenia. A few published case studies emphasise atypical phenomenology in patients with mild ID and autism, who suffer from schizophrenia/psychosis (Petty et al, 1984; Yapa and Clarke, 1989; Clarke et al, 1989; 1999; Sverd et al, 1993). People with autism may speak in idiosyncratic ways (Kanner, 1946), and they may act in ways that may appear as bizarre, even when they are not psychotic. It is reasonable that patients with autism and co-morbid schizophrenia will display more atypical symptoms the more intellectually disabled they are (Ghazuiddin, 2005). However, there are still no published papers on phenomenology of patients with severe ID and autism, and co-morbid schizophrenia (Starling, 2009).

Schizophrenia in people with autism was earlier believed to be non-occurring, a view that was reflected in the diagnostic criteria. Co-morbid autism and schizophrenia was

‘allowed’ for the first time by the diagnostic manuals ICD-10 and DSM-IV, which were released in 1993/1994.

People with more severe intellectual disability who are not able to report their symptoms verbally and suffer from severe psychiatric illnesses for the most part lack adequate services from specialised psychiatric health services (Morgan, Leonard, and Jablensky, 2008). This thesis will explore the use of behavioural equivalents of symptoms of schizophrenia in case identification and decrease of behavioural symptoms will serve as effect measures for evaluation of communication skills in staff members in a specialised psychiatric hospital unit for intellectually disabled adults.

Adults with moderate, severe and profound ID, autism and schizophrenia will during episodes of schizophrenia appear severely disturbed. They display disorientation, disorganised and bizarre behaviour, and agitation or aggression. In most cases, their language skills severely deteriorate. They are more or less unavailable for social contact and display severely reduced global functioning. Thus the patient has considerable problems with task performance, social interaction and self-care. Due to their impaired ability to report their symptoms, they have an increased chance of their mental illness being overseen. Since their actions appear chaotic, both professional health workers and informal caregivers will, for the most part not understand what the patient try to communicate and this may impair the caregiver’s ability to respond correctly.

This thesis will explore the possibility that behavioural disturbances can be used as indicators of schizophrenia in patients *who are severely intellectually disabled* and have severely limited verbal skills. Patients with *mild* intellectual disability will, however, in most cases, be able to report on core features of schizophrenia (hallucinations and delusions), and thought disorder in the form of disorganised speech, can be observed.

This thesis therefore examines a method of case identification and staff communication skills related to the more severely intellectually disabled patients with autism who are thought to suffer from schizophrenia.

### 2.1.1. Symptoms

In this thesis, schizophrenia is referred to as a multi-dimensional disorder, which includes at least three symptom dimensions: positive, negative and disorganisation (Feigner, 1972; Lenzenweger and Dworkin, 1996; Breier and Berg, 1999). This is the most common and accepted view in the field, but there are still discussions about the definitions of the diagnosis of schizophrenia (Deutsch and Davis, 1983). Central to these discussions, is that although patients with schizophrenia share some common core features, they are extremely different from each other regarding the type and intensity of symptoms, the duration of episodes and number of relapses (Bentall, 2003).

When the work with this thesis started in 2003, no publication on behavioural indicators of schizophrenia in adults with ID was available. This forced us to go through available literature where observable symptoms of schizophrenia were mentioned. The result was sparse. A few articles with special interest for this thesis were found (Andreasen, 1979; Cherry et al, 2000; Clarke et al, 1999; Flaum and Schultz, 1996; Hurley, 1996; Kerns and Berenbaum, 2002; Konstantareas and Hewitt, 2001; Rumsey, Rapoport and Sceery, 1985; Rumsey, Andreasen and Rapoport, 1986; Kobayashi and Murata, 1998).

However, clinical experience underpinned behavioural disorganisation as especially important. In the following, symptoms of schizophrenia will be presented related to relevance for the severely intellectually disabled patients with autism. In this group of patients, the psychiatric symptoms are different and appear as atypical when compared with both the normal population and with high functioning individuals with autism (Ghazuiddin, 2005). However, in the more able patients with mild ID and autism, typical symptoms of schizophrenia may be reported.

*Positive symptoms* in schizophrenia, delusions and hallucinations, will for the most part not be reported from the more severely intellectually disabled patients. However, one may expect some sort of altered behaviour to be indicative of auditory hallucinations (Hurley, 1996).

*Negative symptoms* like fatigue, lack of motivation and social withdrawal, may for the most part be observed as behavioural equivalents at all levels of ID. Clinical experience points to the phenomenon of aggravated social withdrawal present when schizophrenia is suspected in patients with ID and autism. However, negative symptoms in more severely intellectually disabled patients have not to date been studied thoroughly (O'Dwyer, 2000).

*Disorganisation*, both in speech and behaviour, may be identified both in the patients with severe ID and among patients with autism. However, disorganised speech will be observable only in patients with a minimal amount of verbal skills (Cherry et al, 2000). Because disorganised behaviour is observable, and of special interest for examination in this thesis, it is important to demonstrate its link to thought disorder, which is considered a core symptom of schizophrenia (Andreasen, 1979; Rochester and Martin 1979; Flaum and Schulz, 1996; Kerns and Berenbaum, 2002).

### **2.1.2. Use of behavioural indicators of schizophrenia**

The use of behavioural indicators increases the chance of misinterpretation (Hurley, 1996; Lee et al, 2003), and severe verbal impairments may endanger the validity of the diagnosis. Behavioural indicators therefore need thorough empirical examination. It is difficult to distinguish between a severe psychiatric condition and other conditions in people with severely impaired verbal skills. For example, adults with intellectual disability and autism often display challenging behaviour like aggression or self-mutilation that may be misinterpreted as psychotic symptoms. Challenging behaviour may also be caused by a patient's medical conditions (e.g., headaches, toothaches, delirium), inability to interact in a social setting, or a negative life event (Rojahn et al, 2004; Chadwick et al, 2005; Hurley and Silka, 2004).

Disorganised behaviour can be observed in patients with medical conditions (Levine et al, 2000; Hellstrøm and Carlsson, 1996; Goodwin, 1997; Milena and Adams, 2001). Thus, behavioural disorganisation limited to these states must not be interpreted as a psychotic symptom.

Taken together, there is a need for thoroughly defined behavioural indicators that differentiate schizophrenia from other conditions in patients who have severe verbal impairments.



### 2.1.3. Obstacles in case identification

The obstacles related to identification of schizophrenia in adults with ID and autism mainly encompasses the following aspects: *diagnostic overshadowing*, *overlapping symptoms*, *atypical symptoms* and lack of agreement on the *use of current diagnostic criteria*.

*Diagnostic overshadowing*: Psychiatric problems have been attributed to the patient's intellectual disability (Reiss, Levitan and Szyszko, 1982; Jopp and Keys, 2001). The same phenomenon occurs in relation to autism. When behaviour change and mood problems are attributed to the autistic condition, psychiatric conditions may be overlooked. This phenomenon is described as *diagnostic overshadowing* (ibid.). Adults with more severe ID and autism will appear to be agitated and exhibit signs of distress in many different situations, not only when experiencing a psychiatric condition. A particular form of diagnostic overshadowing is when the patient's behaviour is explained as characteristics of their personality instead of being symptoms of psychiatric illness (Wadel, 1990). 'Idleness', 'activity denial', 'wanting attention', 'escaping from tasks', or to 'trying to trick' the staff are all commonly used explanations.

*Overlapping symptoms*: There are a number of symptoms that easily can be attributed to both autism and schizophrenia, especially delusions, bizarre behaviour and negative symptoms. Idiosyncratic opinions and a personal way of using words in people with autism can easily be mistaken for delusions. Recent research points to features of thought disorder (manifested by disorganised speech), being present both in individuals with schizophrenia and autism (Rumsey et al, 1986; Konstantareas and Hewitt, 2001; O'Dwyer, 2000). Autistic individuals have cognitive and information-processing impairments, which will affect their thinking and language (Volkmar et al, 2004). Both people with autism and people with schizophrenia will show features of thought disorder, but adults with schizophrenia will tend to show more incoherent speech, pressure of speech and derailment, whereas adults with autism will show more impoverished speech, deviant responses and inappropriate thinking.

Regarding negative symptoms, there seem to be a huge area for overlap (O'Dwyer, 2000). Low social activity, lack of motivation and affect flattening can be attributed to both autism and schizophrenia (Konstantareas and Hewitt, 2001; Lainhart, 1999; Rumsey et al, 1986).

In addition, specific preoccupations may be seen in the two conditions (Rumsey et al, 1986). Stereotyped behaviour has been closely linked to autism, but is also found to be present in schizophrenia (Rojahn et al, 2004; Morrens et al, 2006).

*Atypical symptoms:* The more intellectually disabled the patient is, the more the symptoms may appear as atypical (Ghazuiddin, 2005). Impaired language skills are closely related to occurrence of challenging behaviour and stereotyped activity. Repetitive behaviour and challenging behaviour (violence, damaging of objects, or self-mutilation) has been underpinned as atypical symptoms of psychiatric symptoms in individuals with autism. (Tantam, 2000; Lainhart, 1999; Myers and Winters, 2002).

*Use of current diagnostic criteria:* There is not yet an agreement on the use of diagnostic criteria related to psychiatric co-morbidity with autism. This is manifested by the large variability in prevalence (Howlin, 2000). There are several checklists available for case identification of psychiatric disorders in adults with ID. However, these checklists are for the most part unsuitable for identification of schizophrenia in the autism population, because most of them are constructed to identify autism as one of the mental disorders additional to ID. Two of the most used checklists, DASH II (Matson et al 1991, 1997) and PAS-ADD (Moss et al, 1998), require (some) verbal skills in the patients and may therefore be unsuitable for the more severely intellectually disabled patients. This is also the case with an ICD-10 modified set of criteria for people with ID, the DC-LD (Royal College of Psychiatrists 2001). Furthermore, there are no published studies examining the validity of these checklists related to individuals with autism. A new checklist developed for adults with autism and ID, and suspected psychiatric disorders, *Autism spectrum disorder – comorbidity for adults, ASD-CA* (Lovullo and Matson, 2009), does not include a psychosis subscale.

#### **2.1.4. Symptom level in patients with intellectual disability**

More recent research underpins the total burden of signs and symptoms of severe mental illness as higher in intellectually disabled patients than in neurotypicals (Bouras et al, 2004; Doody et al, 1998; Gustafsson and Sonnander 2004; 2005). It has been suggested that this may be explained by initially weaker reality testing. Patients with additional autistic problems are known to communicate and act in idiosyncratic ways, a phenomenon that is observable even in patients with very limited verbal skills (Kanner, 1946). Patients with autism are known to be cognitively impaired at all intellectual levels. Thus, there is reason to believe that patients with autistic impairments, in addition to the impairments caused by schizophrenia, may need a longer period to become organised, also at times during the day when the patient with ID and autism have a lower level of psychotic symptoms.

Patients with intellectual disability, autism and schizophrenia seem to be in a chaotic state characterised by stress symptoms, anxiety, disorganisation and aggravated social withdrawal. These symptoms, when taken together, seem to reflect that the patient has a totally splintered perception of their internal and external world and is unable to combine the fragments to a meaningful whole.

## ***2.2. Psychiatric care for intellectually disabled patients***

Adults with intellectual disability and additional psychiatric conditions have traditionally had limited access to psychiatric assessment, treatment and care (Bakken and Smeby, 2004; Chaplin, 2004; Raitasuo, Taiminen and Salokangas, 1999). Problems arose after the phasing down of the centralised institutions in Norway for the more severely disabled part of the intellectually disabled population (Nøttestad and Linaker, 2001). This situation is known also in other countries that have reorganised the care for intellectually disabled individuals, such as Great Britain. The multidisciplinary teams that worked in the larger institutions are broken up. The community-based programmes will often result in fragmentation of services (Graham, 2004; Gibbs and Priest, 1999). This is a less than satisfactory situation for the most vulnerable patients, especially those with complex multi-conditions.

In Norway, there has furthermore been an ideological gap between the psychiatric tradition, which for the most part was based on psychodynamic theories and traditional medical practices, and the specialised services for the population with ID. This last group has had an approach based on learning psychology. Newer services tend to include different theories and practices. However, patients experience rejection from psychiatric treatment settings and / or their psychiatric problems are neglected. There is still a need for integrated knowledge from different fields to improve the clinical practice related to the population with ID and autism, and co-morbid psychiatric disorders (Martin et al, 2005). Psychiatric nursing will obviously be a core element of the psychiatric services for psychiatric patients with ID (Pridding, Watkins and Happell, 2007). Care staff represents a majority of the work force in psychiatric services, especially in psychiatric hospitals. The psychiatric care staff will potentially have a number of tasks related to the more severely intellectually disabled patients, like management of patient aggression, advocacy, education of other health workers and coordinating the care (ibid). In the first phase of this thesis, there was a complete lack of papers on psychiatric nursing related to intellectually disabled patients, and, in 2009, such papers represent only a handful of publications.

## ***2.3. Communication with adults with schizophrenia, intellectual disability and autism***

### **2.3.1. Background for examination of staff communication**

Training programmes for improving the communication skills of patients will not work when the patients experience an acute phase of psychotic symptoms. Their severely impaired communication skills are a daily challenge for staff members who work with these patients, both in psychiatric hospitals and community residences (Bakken and Smeby, 2004).

In a special in-patient unit for ID patients with psychiatric disorders at a university hospital in Oslo, a supervising programme has been developed for staff members interacting with patients who are severely disturbed with ID/autism, and who have severe and long-lasting psychiatric disorders. The supervision has included video-analyses of dyadic staff-patient interaction. The programme was evaluated after three years. The video analyses revealed that some of the communication strategies used in daily care for the patients seemed to be effective and thus more therapeutic in helping the patients.

As communication skills in staff members caring for severely intellectually disabled patients have not been examined thoroughly, a study based on the experiences and knowledge gained from this structured supervision was initiated.

### **2.3.2. “Effective communication” – main categories**

Communication is embedded in reciprocity. When health professionals communicate with patients, they usually base the dialogue on an observation and preliminary assessment of the patients’ emotional and cognitive state (Stuart, 2001). In relation to patients with ID and schizophrenia, who are severely impaired, the health professional has to facilitate her communication with the patient to uphold the dialogue (ibid.). Such communication implies that staff members are able to observe the patients symptoms and interpret what they observe. This thesis focuses on how staff members can uphold a dialogue when the patient’s ability to communicate completely breaks down. There is a clear need for such research because there is a lack of studies exploring communication skills related to patients with both more severe ID and psychiatric illness.

In this project, four main categories of staff communication skills were chosen for examination: *response, joint attention, task sustenance and emotional support*.

Related to both the communicative deficits and cognitive difficulties in adults with ID and autism, staff members must aim to uphold a dialogue that is meaningful to the patient (Stuart, 2001; Tjus, Heimann, and Nelson, 2001). Firstly, the caregiver must strive for getting the patient's attention. Attention deficits are present in both autism and schizophrenia, and may often be severe. In such cases the staff member ought to match the patient's cognitive level (ibid.). Individuals with severe and profound ID use nonverbal communication, as gestures, body movements, eye gaze, sounds or facial expressions (Casella, 2005). Communication with severely ID adults may include non-verbal cues, gestures, and electronic devices, flip-boards, etc, that can be adjusted to the patient's communication form and style (Godsell and Scarborough, 2006; Savarimuthu and Bunnell, 2002; Tjus, Heimann and Nelson, 2001). A dialogue with an ID and autistic patient requires ability of the staff member to respond meaningfully when the patient's utterances or gestures are idiosyncratic and hard to interpret (Carter and Iacono, 2002; Porter et al, 2001). Staff must therefore aim at clarity and a high level of contextual saliency in their communication. The patient's idiosyncratic communication and behavioural acts require that the communicating partner know the patient well enough to integrate both contextual and situational knowledge (ibid.).

Cognitive impairments in autism, especially those concerning attention functions, are prominent and cause interaction problems with the patient's social milieu. Attention towards unusual objects and coincidental social impairments urge the staff to strive towards achievement of joint attention on task and interaction. This is difficult, especially if the patient is physically aroused, disturbed or in a confused state. When the staff member aims to achieve joint attention, they must address the patient within the patient's field of attention (Mansfield, 1973). For example, to ensure attention towards the staff it is important to achieve eye contact (Wang et al, 2007). The video counselling in the special department (see above) revealed that if the staff member shouted at the patient from a distance, the chance of causing aggravated disorientation in the patient increased considerably.

It is important that the staff organise social interaction, task performance and provide a choice for the patient. In the most acute phase of schizophrenia, the patient may not be able to initiate interaction, nor be able to fulfil basic needs as food, drink, or going to the bathroom.

The ability to make choices may be strongly affected in the acute phase, and staff may have to decide for the patient what to wear, what to eat, etc. However, when the symptoms are

in remission, making choices will be possible for the patient; if the patient has impaired language skills the staff must be able to arrange for choice making.

For the intellectually disabled and autistic patient, task support will be of vital importance to compensate for the severe fall in functioning that occurs with a schizophrenic experience. The severe disorganisation of people with active psychotic symptoms will normally cause them to derail easily. These symptoms will appear as especially prominent in psychotic patients with ID and autism. Well-trained, routine tasks may be performed inaccurately or not at all. In such cases, the patient will be in need of practical help and support to get through. However, task support does not mean the staff should put pressure on the patient to perform the actual task. On the contrary, Smith and colleagues found high patient response from intellectually disabled adults with behaviour problems when staff members performed a variety of task assistance; such as prompting, demonstration, guidance, arranging for activity, working alongside the patient etc (Smith et al, 2002). The staff members ought to stay close to the patient when task performance is necessary. It is important that staff prepare for task performance, for instance in order to facilitate independent dressing, the patient's clothes should be arranged in a pile with the underwear on top. It may also be necessary to help the patient start dressing by handing over their clothes or by simply dressing the patient if the disorganisation is total. Current psychiatric nursing has integrated the latest information on cognitive impairments and emphasises assisting the patient in task performance (Moller and Murphy, 2001). According to the severe difficulties the patient experience performing tasks when being severely disorganised, the staff ought not to make demands that the patient participate in activities. Demands on participation in activities must be carefully considered when the patient is in remission after being successfully treated for schizophrenia.

When the patient has impaired impulse regulation or is aggressive a highly structured environment is indicated, and help with behaviour regulation by staff may be necessary (Hamolia, 2001). However, such attempts of behaviour regulation that uses for example limit setting, can be insulting and ought to be performed passively, if possible. The following rules are recommended when the psychotic patient is violent: *determine the patient's emotional status before intervening, limit setting ought to be non-insulting, do not raise your voice and, finally, the distance between the patient and the staff member must be close enough to uphold communication but far enough to appear non-threatening* (Stevenson, 1991). The limit setting must be non-affective and conducted without criticism (ibid.). Possible passive limit setting strategies may be diverting or posturing in the doorway so that the patient cannot pass. We

experienced throughout the counselling period (see page 17) that if the patient wandered aimlessly round in the room, or left the table in the middle of a meal, the best strategy for the staff was to remain seated. If the staff started to follow after the patient in order to get him back to the table, sit down, or in other ways become more organised, the patient became more disturbed.

*Emotional support* has been reported to have a significantly positive impact on both physical and emotional problems (Krumholz et al, 1998; Kulik and Mahler, 1993). Adults with ID and autism tend to be emotionally unstable and vulnerable (Volkmar et al, 2004). The knowledge of emotional problems in people with autism has led to the concept of 'affective intonation' as vitally important in nonverbal interaction (Hollins & Sinason, 2000; Stern, 1985). Affective intonation refers to the clinician being able to interpret and respond to the patients' emotional state within interaction (ibid.). Another term for this therapeutic activity is "*tuning*". Affective intonation can be performed in more ways; validation of the patients' emotional state is a well-known intervention in psychiatric nursing (Stuart, 2001), but is a difficult task if the patient does not speak, or speak poorly. Emotional support can be transferred into techniques of interpreting behaviours or facial expressions and responding to these expressions or behaviours, or imitating behaviour of the patient (Hollins & Sinason, 2000; Nadel & Peze, 1993).

The autistic patients' emotional problems may aggravate with an additional schizophrenic condition, as emotional problems is also a symptom of schizophrenia (APA, 1994; WHO, 1993). The emphasis on emotional support in psychiatric care is traditionally associated with psychodynamic tradition (Hollins & Sinason, 2000). Staff communication related to schizophrenia has been especially focused on the emotional disturbances (Mansfield, 1973). Newer research points at communicative strategies from the psychiatric field as useful also in the care of ID. Lam et al examined expressed emotion (EE) in carers for ID children and found that emotional supportive acts influenced stress in the families in a positive way (Lam et al, 2003).



### **2.3.3. Implications for recommended staff communication**

Examination of staff communication will potentially have the following implications: Firstly, if these targeted communication skills prove to have a positive impact on the patient's symptom level, it may entail a more therapeutic way of communicating with severely disturbed patients. Secondly, communication skills that are studied (see earlier) and shown to be effective, may have the potential to be applied during the training and counselling of staff who care for this group of patients. Both adults with ID and autism and adults with schizophrenia are severely vulnerable. It is most likely that this vulnerability increases when schizophrenia, and ID and autism co-occur. Another recent advancement involves teaching and consulting the patient's family.

### **3. AIMS AND RESEARCH QUESTIONS**

#### ***3.1 Main project objective***

As in most clinical research, the main aim of the present project was to contribute to the development of relevant and hopefully more effective treatment strategies. Such strategies will however rely on 1) available methods of identifying the patient's suspected condition in a valid and reliable manner, 2) available and relevant treatment methods, and 3) available methods of evaluating the effects of treatment and interventions.

The process of developing satisfactory treatment strategies, which fulfil these three demands, may hopefully lead to a more thorough understanding of the phenomenon of schizophrenia in combination with ID and autism. The studies presented in this thesis may be regarded as pilot studies and modest steps in this direction.

In the current project the three points listed above led to formulation of three main research questions:

#### ***3.2 Main research questions***

1. Is disorganised behaviour a reliable and valid indicator of schizophrenia (as defined in current diagnostic practice) in adults with intellectual disability and autism (paper I and paper IV)?
2. Is it possible to develop a tool for observation of staff communicative skills related to adults with ID, autism and schizophrenia that may be reliably and validly applied in natural settings? (paper II)
3. Are the communicative skills originally selected on the basis of constituting "*effective communication*" (paper II) truly effective in decreasing disorganised behaviour and increasing initiatives in the patients? (paper III)

## 4. MATERIAL AND METHODS

### 4.1 Measures

Due to the lack of agreement in the use of criteria for assessment of schizophrenia in the more severely intellectually disabled patients and no standardized rating scales available for assessment of staff communication for this group of patients, measures suitable for answering the research questions were specifically developed for this project. The measures were constructed from behavioural indicators of *schizophrenia in ID* (especially behavioural disorganisation and social withdrawal) and presupposed so-called *effective staff communication*.

Measures from four different sources are included:

1. Items from the Psychopathology in Autism Checklist (PAC)
2. Observations of indicators of disorganised behaviour in natural settings
3. Observations of indicators of effective staff communication in natural settings
4. Qualitative descriptions of symptoms based on observations

#### 1. The Psychopathology in Autism Checklist (PAC)

The Psychopathology in Autism Checklist (PAC) is a caregiver-completed checklist constructed to assist the process of clinical assessment, diagnosis and management of psychopathology in adults with autism and ID (Helterschou, Bakken and Martinsen, 2008; 2009). The PAC is still being developed (ibid). The measures from the PAC version used in this thesis comprise five items measuring behavioural disorganisation and 18 items measuring distress symptoms. The items in the PAC are carefully selected on the basis of three main criteria; 1) they should be observable symptoms independent of verbal report, 2) they should minimize diagnostic overshadowing and 3) they should *measure psychiatric disorders as these are defined and used in current diagnostic practice*. A more detailed discussion of this instrument is presented in paper I.

The measures from the PAC version used in this thesis comprise of five items measuring behavioural disorganisation, and 18 items measuring distress symptoms. The five behavioural disorganisation items are included in the PAC psychosis subscale, encompassing altogether 10 items (see appendix for all ten items). As this thesis is examining schizophrenia

and behavioural disorganisation in particular, it was chosen not to use all of the PAC items. The distress-symptom subscale was included, as we wanted to examine whether the study group obtained higher distress-symptom scores.

Most psychiatric symptoms may be regarded as reflecting a continuum, shown to be present both in the normal and in the “psychiatric problem” part of the population (Bentall, 2003). The symptoms are ranging from very mild in the normal cases, to moderate or severe in the afflicted cases. Although psychiatric symptoms commonly are rated by professionals as present or not, it may be easier to assess to what degree behaviours (symptoms) are shown. To rate a certain behaviour as present or not, may be extremely difficult for untrained observers, and even more difficult when the patient barely communicates verbally. For this reason, the scale values of the PAC items range from 1 through 4.

In paper I the main objective was to investigate the construct validity of this instrument by examining if patients with a known psychiatric diagnosis would score as expected on the relevant PAC dimensions. The only available estimate of reliability was Cronbach’s Alpha, which was found to be acceptable for the relevant dimensions (behavioural disorganisation and distress symptoms).<sup>1</sup>

## **2. Observations of indicators of disorganised behaviour in natural settings**

The measures were chosen to cover symptoms of schizophrenia in severely disturbed patients with ID and autism. These symptoms needed to be observable and it was therefore mainly focused on disorganised and organised behaviour. Behavioural disorganisation was operationalised according to the categories described by Flaum and Schultz (1996) and adapted to the target group: *derailment* (of task), *aimlessness*, *repetitive behaviour*, *rocking*, *self-destructive behaviour*, *violent behaviour*, *crying/shouting*, and *meaningless response*.

Measures of disorganised speech were also defined. The measures of disorganised speech included: *incoherence*, *derailment* and *pressure of speech*.

Since most patients with autism and schizophrenia probably will show aggravated social withdrawal, patient initiatives towards staff were included in the study. The initiatives were scored as *organised behaviour*. Organised behaviour was operationalised as: *targeted approach/behaviour*, *initiatives from the patient*, *meaningful answers* and *following directives*. The measures of *organised behaviour* are presented in more detail in papers II, III

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1. Reliability estimates for the entire PAC are presented in the PAC-study (Hellerschou, Bakken and Martinsen, 2009).

and IV. Data used in papers II, III and IV were collected by observing video-taped recordings of patient-staff interactions. In addition, patient utterances were transcribed to aid scoring of disorganised speech.

### **3. Observations of indicators of effective staff communication in natural settings**

Indicators of “effective” staff communication were chosen on the background of existing papers on staff communication skills related to adults with ID and autism, and schizophrenia, respectively – see 2.3.2 for details concerning the chosen indicators. In accordance with the theory (see earlier), “effective” communication was operationalised by using a three-step procedure (Carmines and Zeller, 1994). Firstly, the concept was defined as *staff communication that decreases the patient’s symptom level*. Secondly, a data search for suitable measures that would reflect the content of the concept was conducted. The searches (with key words: *effective staff communication, psychiatric nursing, learning disability nursing, schizophrenia, psychosis and disorganisation*) resulted in a few relevant papers from the field of psychiatric nursing, or LD nursing, respectively (Carter and Iacono, 2002; Cascella, 2005; Godsell and Scarborough, 2006; Hamolia, 2001; Manfields, 1973; Moller and Murphy, 2001; Porter et al, 2001; Savarimuthu and Bunnell, 2002; Smith et al, 2007; Stevenson, 1991; Stuart, 2001; Tjus, Heimann and nelson, 2001; Wang et al, 2007). These papers, in combination with clinical experience, resulted in the four main categories of “effective” staff communication: *meaningful response, joint attention (called attention sustenance in paper III), task sustenance* and *emotional support*. Finally, as a third step, the skills were made observable by defining a number of sub-categories. The instrument was further examined in a pilot-study, including one patient with severe ID, autism and schizophrenia, interacting with staff in natural occurring settings. The measures were tested through a counselling programme in the special unit, including 14 counselling sessions. Based on experiences from the pilot study some sub-categories were excluded due to extremely low rates of occurrence and others had to be reformulated to achieve consistent interpretations. This three-step procedure ended up with a formulation of the 19 sub-categories presented in detail in papers II and III. As for patient behaviour, observational data used in the papers were based on the videotaped recordings of patient-staff interactions.

Three of the staff sub-categories were scored on episode level; *adjust tempo, prepare for activity*, and *adjust emotional level*. However, due to the short duration of episodes, these categories were scored too infrequent to allow further analyses.

## Observational data

With the exception of some qualitative information described below, the data used in this thesis are based on observations of patient- and/or staff behaviour. While the PAC data are based on informal and unstructured observations by untrained observers, the data used in papers II, III and IV is based on observations in structured and planned settings by trained observers. Due to space limitations, the discussions of scoring criteria and designs used in papers II, III and IV are not very comprehensive, and some further comments will hopefully be useful for readers of this thesis.

When observing behaviour in real life settings, two basic designs are very often used; the ‘time-sample’ and the ‘event-sample’ designs (Bakeman, 2000). When collecting time-sampled observations, continuous time is split in convenient sampling intervals. One could for example decide that every 30 seconds, behaviour occurring at that moment or in the time-interval prior to the relevant time-marker, should be scored. If the frequency of the behaviour of interest is low, this design will of course result in numerous ‘non-existent’ scores. If event-sampled observations are used, one would score every event when it occurred and only then. If this design is used, the data will carry no information concerning when it occurred, how often it occurred, or the length of the time intervals between occurrences. In the current project we opted for a ‘best-of-both-worlds’ solution by video-recording the behaviour and scoring event-sampled observations from the recordings. This way we could always reconstruct time from the tapes, and we could if necessary, perform multiple independent observations of the same recordings.

When collecting data a clear definition of the ‘observational unit’ is necessary. When observing behaviour this is not a trivial decision. What constitutes an ‘utterance’, an ‘action’ or a ‘transaction’? In the current project we pragmatically defined the smallest unit of observation as *a behavioural act that could be described by one of the categories of the scoring systems applied*. These acts were coined ‘turns’. This implies that all behavioural acts observed are not necessarily scored and all ‘turns’ scored are not necessarily responded to. In principle we could experience long sequences of only patient or staff ‘turns’. If a ‘turn’ is responded to we coined it a ‘*transition*’ (some readers may prefer ‘transaction’).

Recorded data of 15 turns could then appear like this:

	1	2	3			4	5	6	7		8	9	10	11	12	13	14	15	
	S	S					S		S	-	S	S			S				-
-			P	-	-	P		P					P	P		P	P	P	

S = staff turn, P = patient turn, - = behaviour not scored

In this example we would have 7 staff-turns, 8 patient-turns, 4 staff-patient transitions, and 3 patient-staff transitions.

In papers II, III and IV, the term '*episode*' is also used. An '*episode*' is defined as *a behavioural sequence starting with an initiative from either patient or staff and ending when interaction is suspended for a predefined time interval (>10 seconds)*.

Depending on the research-questions, data has been analysed at different levels (turn, transition or episode) - the 'unit of analysis' is not always the 'observational unit'. This may be somewhat confusing when reading the three papers and warrants more explicit treatment.

In **paper II** the chosen measures are based on episodes. A total of 370 episodes across 4 patients were used. In each of these episodes staff and patient turns of different types may be observed a varying number of times. The raw number of occurrences may of course be of interest, but this number will obviously depend on the duration of the interactional sequence. To achieve a measure more independent of duration, the number of turns scored as belonging to a certain category (j), was counted and the relative frequency (percentage) of that category was computed as  $F_j / N_e$  – where  $F_j$  = frequency in category j and  $N_e$  = total number of turns in the episode. Our chosen measure is thereby *the relative frequency of different staff and patient behaviours within episodes*. The aim of this study was primarily to investigate the properties of the scoring instrument, not primarily as a research instrument, but as a practical tool in staff education. If this instrument is to be of practical use, it should aid the understanding of patient-staff interactions (sequences). We were trying help in answer the 'whoops.... what happened now' question by constructing a measure that could be used to describe the characteristic qualities of *episodes*. To examine inter-rater agreement, a subset of 37 episodes was independently scored by two observers. For each category a 37 (episodes) by 2 (observers) matrix containing relative frequencies was prepared and correlations between observers were computed. Results showed that one of the observers systematically scored some categories as occurring more often but that agreements on which episodes showed the higher and lower occurrences as measured by the correlations was satisfactory for most of the

categories. Further comments on these measures are found below and in the synopsis of paper II.

In **paper III** where the effects of staff behaviour on patient behaviour and the effects of patient behaviour on staff behaviour were our main focus, ‘turns’ were chosen as units of analysis. As shown above, not all staff turns are followed by patient behaviour and not all patient turns are followed by staff behaviour. In the current paper only transitions were selected for analysis. The transitions were cross-tabulated and for relevant staff behaviours the conditional probabilities of different patient behaviours were computed. The conditional probabilities were computed as  $C_{ij} / S_i$  – where  $S_i$ =total number of staff behaviours of type i and  $C_{ij}$ =number of patient behaviours of type j following staff behaviours of type i. The same computations were performed for conditional probabilities of staff behaviours:  $S_{ij} / C_i$  – where  $C_i$ =total number of patient behaviour of type i and  $S_{ij}$  = number of staff behaviours of type j following patient behaviours of type i.

In **paper IV** our main focus was on co-occurrence of disorganised speech and disorganised behaviour. This co-occurrence would be extremely difficult to investigate on turn level and episode was chosen as the unit of analysis.

In paper IV, only patient data was statistically analysed. However, staff utterances were indirectly used to evaluate whether patient utterances were linked to staff utterances. The measures of behavioural disorganisation were the same as in the communication study. The measures of disorganised speech were defined for paper IV especially: *incoherence*, *derailment* and *pressure of speech*. These measures were based on described features of disorganised speech (Andreasen, 1979), and observations of these features uttered by the one participating patient during the video-recordings. All utterances were transcribed from the video-recordings, and then scored from text.

If at least one instance of disorganised behaviour was observed, the episode was scored as ‘disorganised’. The same applied for disorganised speech. Eighty-four episodes sampled from patient-staff interactions with one patient were analysed (Kazdin, 1982). Both disorganised behaviour and disorganised speech inter-rater agreement on occurrence was high ( $Kappa=.77$  and  $Kappa=.87$  respectively). Co-occurrence of disorganised speech and disorganised behaviour was evident in 67% of the episodes and the conditional probability of disorganised speech given disorganised behaviour was .78. This was interpreted as evidence of a close relationship between these phenomena and, since disorganised speech is a key feature of schizophrenia, it was argued that disorganised behaviour may be a viable indicator of schizophrenia in adults with ID and autism.



### **Some comments on the reliability and validity of the observational measures**

While reliability has a clear (although not undisputed) definition in classical measurement theory as the proportion of variance in observed indicators due to variance in latent, unobservable phenomena, the definition is more problematic in studies applying observational data. Reliability of observational measures is often estimated by some sort of agreement measure – proportional agreement, correlation coefficients like the Phi-coefficient, Cohen's Kappa, the Jaccard coefficient, etc., and inter-observer agreement are often used interchangeably with reliability. Lack of agreement among observers may however have two sources. Two observers may disagree due to random measurement error – or they may disagree because they are systematically not observing the same behaviour and/or they are systematically not using the scoring instruments the same way. In the latter case disagreement would indicate problems connected to validity rather than to reliability. Keeping in mind the measurement theoretical definition of reliability as 1-proportion random measurement error, agreement will therefore only be an estimate of reliability if low validity is ruled out as an explanation of disagreement. This may be illustrated by the measures used in paper II. In this paper the measures used were *the relative number of occurrences of a specific type of behaviour within an episode*. As reliability (and validity) always will have to be estimated for the measures used, the estimates presented in the paper were based on inter-observer agreement on the relative number of occurrences and this was found to be satisfactory. Some disagreement about scores on 'turn-level' will be expected and this will in no way invalidate the measures. An analogous situation would arise when comparing two person's scores on an aptitude inventory – they may have identical numbers of 'correct' answers, but not necessarily always have 'correct' scores on the same items. This would obviously not invalidate the overall 'aptitude-score'. If the two observers are using the scoring instrument randomly, this would of course not result in systematic correlation between aggregated scores as sums of random variables are as random as the variables summed, so this may be ruled out by the high agreement on number of occurrences. One could, however, argue that it is theoretically possible, although extremely unlikely, that two observers may *systematically* agree on the numbers observed while still be *systematically* scoring different behaviours or *systematically* using different criteria, and in that case the validity of the measures could be seriously questioned. To examine this in more detail the data used in paper II were scored by two independent observers and agreement was examined at 'turn-level'. Agreement was clearly satisfactory for all categories even at 'turn-level' with Cohen's Kappa for staff-behaviour

ranging from .60 to .81 (mean=.74) and Kappa for patient-behaviour ranging from .69 to .73 (mean=.69). The results are presented in more detail in the synopsis of paper II.

#### **4. Qualitative descriptions of symptoms based on observations**

As the main purpose of the PAC study was the validation and refinement of the PAC screening instrument, it was of crucial importance to obtain a comprehensive phenomenological description of behavioural disorganisation in ID. Such descriptions are not readily available. Qualitative data may give more phenomenological information than a symptom checklist, and the researcher is not tied up in the data collection process, as is the case when collecting quantitative data (cf. Kvale, 1996). The qualitative data encompass information from the case files of the eight patients in the study group. The case files include both medical and nursing documentation from current and previous admission in the special psychiatric unit for ID where this study was conducted. Case file information was also collected through interviews with responsible psychiatrist and members of the nursing staff in the hospital wards in the special psychiatric unit for adults with ID.

The qualitative data collected encompassed features of both behavioural disorganisation and other psychotic symptoms. When quantitative and qualitative data were analysed, symptoms indicated by quantitative and qualitative analyses were compared. These analyses showed that behavioural disorganisation is observable both with PAC and qualitative information, but that the qualitative information gave additional information, for example on sequential problems, which are not encompassed by the PAC. Another example is hallucinations. The qualitative analyses revealed that 7 of the 8 people in the study group exhibited varying features of suspected hallucinations that were not covered by the PAC. The qualitative data supplemented and supported the findings from the PAC-analyses, namely that behavioural disorganisation is prominently present in these patients, and the qualitative data also supported that behavioural disorganisations is concurrently present with other symptoms of schizophrenia in the patients in the study group.

## 4.2 Samples and settings

The PAC study (paper I)

### *The patients*

For the PAC study (paper I) forty-seven adults with intellectual disability, autism and schizophrenia were recruited (see table 1 below for an overview). Clinicians in the research team reconsidered all the psychiatric diagnoses, including autism, additional to ID, using DSM-IV criteria. The PAC measures were not used in this procedure. During the recruitment phase, which lasted for almost three years, four of the participants originally assumed to be mentally healthy were found to have undetected psychiatric problems. These participants were excluded from the study. The patients with psychiatric diagnosis in addition to autism (33 patients) were re-diagnosed and eleven patients with psychosis were identified. Of these eleven patients, three patients were re-diagnosed to be suffering from affective psychosis (mania) leaving eight patients diagnosed with schizophrenia. These eight patients were referred to psychiatric hospitalisation due to long term display of severe challenging behaviour, and they suffered from severely impaired functioning related to social functioning and task performance. They were recruited as in-patients and given psychiatric treatment in the study period. This group of eight patients was chosen as *the study group*. To be able to study both convergent and divergent validity, two comparison groups were formed.

The first comparison group (*the plain autism group*) included 13 adults with both ID and autism diagnoses, but no obvious psychiatric disorder. The participants in the plain autism group were recruited through community services and the Norwegian autism association.

The second comparison group (*the mixed group*) was comprised of 19 patients with ID, autism and various non-psychotic psychiatric disorders; depression, anxiety, or obsessive-compulsive disorder. The participants in the mixed group were recruited from different specialised health services.

All diagnoses were conducted prior to the study, not using the PAC, and by personnel blind to the purpose of the study. The patients were clinically assessed using DSM-IV.

Table 1.1: Samples and measures of the PAC study

Groups	N (total =47)	Diagnoses	Measures
Study group	8	ID, autism + schizophrenia	Distress symptoms, behavioural disorganisation + qualitative data
“Plain autism” group	13	ID and autism	Distress symptoms, behavioural disorganisation
“Mixed group”	19	ID, autism and depression, anxiety or OCD	Distress symptoms, behavioural disorganisation
Excluded by confirmed Mania	3	ID, autism and psychotic mania	Not analysed
Excluded by suspected psychiatric illness additional to “plain autism”	4	ID, autism and possible psychiatric illness	Not analysed

### *The informants*

The 40 selected patients were rated on the PAC by two observers. To increase validity, inclusion criteria for informants were that they had known the patient for more than one year and that they had observed the patient in daily interaction. These informants were mainly staff or family members and blind to the purpose of the study.

### The observational study (papers II, III and IV)

The setting chosen for the observation study was a specialised psychiatric in-patient unit for intellectually disabled patients in a university hospital (Bakken and Smeby, 2004). This unit was chosen because it was a unit specialised for assessment and treatment of patients with complex psychiatric conditions. Since 2002, this department has been the location of a project that aims to develop psychiatric services for patients with ID and autism (Bakken, 2007).

### *The Patients*

Four patients were recruited. Inclusion criteria were clinically assessed diagnoses of intellectual disability, autism and schizophrenia and these four patients were the only patients in the chosen setting fulfilling the inclusion criteria. To ensure valid diagnoses, a fundamental premise for assessment and evaluation of staff communication skills, the patients were re-diagnosed. The patients were re-diagnosed independently by two experienced clinicians, by reviewing case files, interviewing core staff, and by clinical observation. Exclusion criteria were epilepsy or other neurological disorders associated with psychotic features, i.e., hallucinations or disorientation (Gillberg, 1995). The patients were mildly to severely

intellectually disabled, and between 31 and 52 years of age. The patients' psychotic symptoms were measured previous to the video recordings, using the Positive and Negative Syndrome Scale, PANSS (Kay, 1987). PANSS' scores indicated active psychotic symptoms in all four patients. None of the four patients were in their most acute phase during the six months video-recording period.

The one patient participating in study four was well known to the research team. During the course of study she experienced (at least) her third schizophrenic episode. Between schizophrenic episodes she showed typical autistic behaviour, but not disorganised speech or behaviour as described in paper IV.

### *Staff*

During the data collection period, the special unit employed approximately 100 staff members. The pilot study (see page 26) revealed different and individually consistent communicative styles. To secure variability in staff communication, a considerable number of employees were therefore included.

To avoid systematic sampling of staff members and patient-staff interactions, time intervals during daytime between nine and three pm were chosen for observation. Both staff and patients were blind to the planned recording dates and hours and the video photographer arrived at the wards unannounced. Presumptively this procedure resulted in a quasi-random sample of interaction sequences (episodes), in paper II inaccurately described with the term 'random sample'. During the data collection period, recordings were conducted 1-3 times a week.

This procedure resulted in a sample of 34 staff members with varying years of work experience and 71 video recordings of many different situations; including morning rituals, meals, dressing, walking, school lessons, various activities at the day-centre and social arrangements like afternoon coffee or music groups. Approximately one third of the entire staff in the special unit was included. The sample was comprised of nurses (10%), nurse's aides (73%), and nonqualified staff members (17%). Their average work experience was 5.6 years (range: 10 months to 16 years).

## 4.3 Analyses

### Quantitative analyses

#### *Paper I*

Cronbach alphas were used to estimate the reliabilities of the behavioural disorganisation and distress symptom scales. Mean inter-item correlations were used as measures of internal consistency. Differences in PAC scores of behavioural disorganisation and distress symptoms between the three groups investigated were analysed by one-way analyses of variance (Anovas) with Bonferroni corrected multiple comparison tests. The observational units in this study were patients and the total number of observations was 40. The study group (n=8) was scored with the PAC on two occasions - before and after psychiatric treatment. To analyse differences across time in scores on behavioural disorganisation a Wilcoxon signed rank test was conducted. Due to the low number of observations, a non-parametric test was considered appropriate.

#### *Paper II*

The relative frequencies of relevant patient and staff behaviours *within episodes* were our chosen measures. A total of 370 communicational episodes encompassing 2546 communicative acts from 4 patients and 34 staff members were the observational units in this study. For each of these episodes the relative observed frequencies (in percentages) of the relevant behaviours were computed. To examine inter-rater agreement, 37 episodes were randomly selected from the 370 episodes included in the study, and scored by a second observer. Inter-rater agreement on these relative frequencies was examined (paper II, table 3).

A more lenient criterion of agreement would be the “rank-profile ordering” of these relative frequencies. This means that although one observer could observe fewer instances of a particular behaviour than the other observer, he/she could still regard this as equally “dominant”. For example from paper II, table 3 it is obvious that the mean relative number of “meaningful answers” are lower for observer 2 (18.5) than for observer 1 (23.3). “Meaningful answer” is however the most prominent behaviour for both observers. Inter-rater agreement on these relative frequencies across episodes was computed as ordinary Spearman rank-order correlations.

While we were primarily interested in *the number of occurrences observed*, it could be of interest to examine the agreement on *occurrence of particular behavioural acts*. To examine agreement on this level the observers must necessarily observe the same behavioural

acts (Bakeman and Gottman, 1997, ch.4). To accomplish this, the second observer rescored the exact same behaviours observed and scored by the first observer. Inter-rater agreement was analysed by cross tabulating the two observers and computing Cohen's Kappa.

### *Paper III*

In paper III our main focus was on the relationships between patient and staff behaviours. Patient and staff behaviours were scored by an event-sampling procedure where any number of patient behaviours may be followed by any number of client behaviours. The data used in paper III comprised only 'transitions' - that is; alternating patient-staff behavioural acts (n=760). Data were analysed by a lag-sequential procedure (Bakeman and Gottman, 1997, Bakeman, McArthur and Quera, 1996, Allison and Liker, 1982), making it possible to examine sequential correlation (for example  $P\{\text{patient behaviour}_i | \text{staff behaviour}_j\}$ ). Patient-staff co-variation was measured by phi-correlations.

### *Paper IV*

Observer agreement was calculated separately for disorganised speech and disorganised behaviour by Cohen's Kappa (Sim and Wright, 2005). Patient's utterances from the 84 episodes were transcribed. The transcriptions were rated for presence of disorganised speech by two observers. Presence of disorganised behaviour was scored by both observers from the video-recordings. Due to observing and scoring from video-recordings being time consuming, the second observer scored approximately every second of the recorded episodes, i.e. 40 episodes.

The relationships between disorganised speech and disorganised behaviour and subcategories were analysed by cross- tables. For tests of significance, Pearson Chi-square and Fisher's exact tests were performed.

All quantitative analyses were performed with SPSS. Except for paper I where people were observed, all analyses are based on observations within people. This will obviously raise a question of the independence of observations - the most critical assumption in standard significance tests. This is a general problem in studies of communication where observations are necessarily sampled from the same individuals across time. In all papers, we have chosen to put little weight on standard significance tests. When they are used, they are used only as crude indications of the results showing systematic tendencies and we urge the reader to interpret the reported p-values in the same cautious manner.

## Qualitative analyses

Qualitative analyses were conducted for the symptoms of the eight patients in the study group. All information from interviews with psychiatrist and main staff members, and from case files, were analysed according to categories corresponding to the criteria for schizophrenia in DSM, both A criteria (characteristic symptoms) and B criteria (impaired functioning). As people with ID and additional psychiatric illness are known to show severe distress symptoms (Gustafsson and Sonnander, 2004), information on distress symptoms were also included in the qualitative analyses. Only distress symptoms that were prominent and possible to observe were included in the analyses.

From all interviews, notes were taken during the interview sessions. Information from case files were systematised according to categories corresponding to DSM-IV criteria. All qualitative information were analysed through a four-step procedure. Analysing data in several steps is a widely used method in qualitative research (Morse and Field, 1995).

Step 1: All written information were organised in eight sections, one for each patient. As behavioural disorganisation was the main object of investigation and to our knowledge not has been investigated in patients with ID earlier, features of behavioural disorganisation were especially emphasized.

Step 2: All behaviours that could potentially be features of behavioural disorganisation were listed for each patient.

Step 3: These features were organised in five categories according to the work of Flaum and Schulz (1996). The five categories were *task derailment*, *aimlessness*, *problem with sequencing chains of behaviours*, *disorientation* and *bizarre motor activity*.

Step 4: All written information were analysed again according to other DSM-IV criteria for schizophrenia and systematised under the following categories; impaired speech (disorganised speech in DSM-IV), suspected hallucinations (hallucinations in DSM-IV), delusions, social withdrawal (behavioural equivalent to negative symptoms in DSM-IV).



#### **4.4 Ethical considerations**

There are special considerations involved related to research involving individuals with cognitive impairments, especially when these individuals are severely intellectually disabled and can not legally consent or refuse participation in a study. Therefore, we informed, asked, and then received consent for participation from the close relatives (parents or siblings).

##### *Paper I*

Permission to conduct the PAC pilot study has been given by the Eastern Regional Ethical Board of Norway. Permission was also given by the Norwegian Science of Community Data Services (SND).

All of the families of the 47 people with autism involved were informed and consented in writing to participate in this study.

##### *Papers II, III and IV*

Permission to conduct the staff communication study was given by the following authorities: the director of the hospital was informed and approved of the study; the four families/guardians were informed and they approved; all staff members gave their informed consent. One patient gave informed consent. The other three patients are not capable of giving consent. They were informed prior to all video-recordings about the recording. The Eastern Regional Ethical Board of Norway has given permission to record patients and caregivers using a video camera. All original data (videotapes) will be destroyed when the study is completed, as required by Norwegian law.

When this study was planned, the Norwegian Autism Network was given a general permission by the Norwegian Science of Community Data Services (SND), to include participants in projects initiated by the network. This permission was not renewed after 2003. New permission from the SND was not sought for the present study. However, as these patients (and staff) were admitted at Ullevaal University Hospital (now Oslo University Hospital Ullevaal), the hospital's Privacy Protection Supervisor was contacted in retrospect, and confirmed that permission would have been given, if applied prior to the study conduction.

#### **Advantages and disadvantages for the participants**

Advantages for the participants in the PAC-pilot study were the re-evaluation of psychiatric diagnoses by the research team and thereby their diagnoses were either confirmed

or rejected with suggestions for more suitable psychiatric diagnoses. The health services providing treatment and care for the participants were given the results from the study, and could then conduct further psychiatric assessment and treatment. The eight patients in the study group received a thorough diagnostic assessment and treatment of psychotic illnesses. There were no obvious disadvantages for the participants in the PAC-study.

For the participants in the staff communication study, the advantages were closely related to the feed-back given regarding relevant communication strategies revealed through the numerous video-recordings. The patients also received a thorough diagnostic assessment to confirm their psychiatric diagnosis. The possible disadvantages may be related to the frequent video-recordings. As three of the patients barely spoke through the observation period, it is difficult to know whether they experienced the video-recordings as annoying. The one patient, who is mildly ID, was invited to watch the video-recordings when the observation period was ended and she had regained her non-psychotic functioning. She wanted to watch only one recording and later she stated that it was interesting to watch herself “as a whole person both in length and in width”.

## 5. SYNOPSES OF THE STUDIES with additional analyses and results

In this section, synopses of the four published papers are presented, with additional analyses and results not presented in the four papers.

### 5.1. Paper I

Bakken, T.L., Friis, S., Lovoll, S., Smeby, N.A., Martinsen, H. (2007) Behavioral Disorganisation as an indicator of psychosis in adults with intellectual disability and autism. *Mental Health Aspects of Developmental Disabilities*, 10:2, 37-46.

**Background:** In adults with intellectual disability and autism, schizophrenia is rarely detected due to misinterpretation of psychotic or negative symptoms being autism or impaired communication skills. Behavioural indicators are needed.

**Aim:** The aim of this study was to investigate behavioural disorganisation as an indicator of schizophrenia.

**Sample:** Forty-three adults with intellectual disability, autism, and a formerly diagnosed psychiatric disorder were recruited. The participants were divided into three groups; the study group encompassing eight patients diagnosed with schizophrenia, a plain autism group (13 participants), and a non-psychotic psychiatric group (19 participants). Three participants were excluded from further analyses due to a diagnosis of bipolar disorder.

**Method:** Scores on the Psychopathology in Autism Checklist (PAC) were analyzed and further compared to qualitative data based on case information on the 8 adults with diagnoses of schizophrenia.

**Analyses:** The qualitative analyses were conducted as a four-step procedure based on the criteria for schizophrenia in DSM-IV. Behavioural disorganisation was measured as the mean score of five items. Distress symptoms were measured as the mean score of 18 items. Reliability was estimated by Cronbach's alpha. Groups were compared by ANOVA.

**Results:** The schizophrenia-group showed significantly more disorganised behaviour than both the "plain autism" group and the non-psychotic psychiatric group. Bonferroni corrected multiple comparisons showed statistically significant differences between all three groups. The behavioural disorganisation scale showed satisfactory reliability (Cronbach's alpha=.81) and internal consistency (mean inter-item correlation=.47). The same was found for the distress symptoms scale (Cronbach's alpha=.92, mean inter-item correlation=.41).

The qualitative data were analysed according to DSM-IV criteria. The results of these analyses are presented in table 1 in paper I. The analyses showed that the eight patients with schizophrenia displayed 4 or five features measuring behavioural disorganisation (mean 4.5). Impaired speech (disorganised speech) was observed in seven patients with schizophrenia (patient nr. 8 is profoundly ID and does not communicate verbally). Incoherence was observed in five patients, impoverished speech in seven patients. Delusions were observed in one patient only. Suspected hallucinations were observed in seven patients. The following behaviours were observed as a basis for this suspicion in these seven patients:

- Complains about ear-pain without otitis or other somatic state confirmed
- Covering ears when shouting concurrently
- Staring at fixed spots and concurrently being unreachable for contact
- Anxiety reactions when staring at fixed spots or objects
- Self-mutilation (especially head-banging) while covering ears
- Strange sounds which are not normally uttered by the patient
- The patient is 'jumpy' without any visible reason
- Hard to get in touch with the patient when he/she shows signs above.

Moderate or severe social withdrawal (negative symptom) was observed in all eight patients. Severely impaired global functioning was observed in all eight patients. Distress symptoms were observed in all patients; insomnia in eight patients, symptoms of anxiety in eight, irritability/ anger in two, aggression in six, weight loss in six, unrest in three, yelling in three, self-injury in two and urine incontinence in one patient. The number of features of distress symptoms in the eight patients ranged from three to six, with a mean of 5.1.

The results of the qualitative analyses indicate an association between behavioural disorganisation and distress symptoms, as all the eight patients with schizophrenia showed both severely disorganised behaviour and prominent distress symptoms.

During the systematising of the case information, it was revealed that psychiatric treatment had also reduced psychotic symptoms other than behavioural disorganisation (this information was collected through case files). *Suspected hallucinations* were reduced in six of seven patients, *speech* was reported markedly less disorganised in all seven patients with verbal capacity. Two of these seven patients did not speak during the psychotic episode. Both started speaking after treatment. The one patient with delusions still talked about her delusional beliefs after treatment, but the monsters that she saw – which was the content of her delusions - did not frighten her anymore. Regarding *social withdrawal*, all eight patients

were reported to have regained their pre-psychotic social behaviour. For six of the eight patients, it seemed that the *grossly impaired functioning* that they displayed through the psychotic period lasted longer than the other symptoms such as disorganisation and distress symptoms. There were however some lack of information on this subject in the case files. Related to distress symptoms, information related to anxiety and weight loss was found with regard to all eight patients, which showed that all eight patients had gained (some) weight and showed less anxiety reactions after treatment.

**Conclusions:** Gross behavioural disorganisation occurs in formerly diagnosed patients with schizophrenia. Behavioural disorganisation was displayed both by PAC scores and through qualitative analyses of case reports. The results of the reliability analyses and statistically significant differences between the study groups and the comparison groups support the validity of behavioural disorganisation as an indicator of schizophrenia.

## **5.2. Paper II**

Bakken, T.L., Eilertsen, D.E., Smeby, N.A., Martinsen, H. (2008) Observing communication skills in staffs interacting with adults suffering from intellectual disability, autism and schizophrenia. *Nordic Journal of Nursing Research and Clinical Studies*, 28:1, 30-35.

**Background:** Co-morbidity of intellectual disability, autism and mental health problems, generate a need for integrated knowledge from both intellectual disability nursing and psychiatric nursing.

**Aim:** The aim of this paper was to examine the usability and reliability of measures developed and designed to observe communication skills in professionals caring for patients with intellectual disability, autism and schizophrenia.

**Sample:** 370 episodes of staff-patient interaction were observed and scored. These episodes included 2546 staff and patient turns (1169 staff turns and 1377 patient turns) from 4 patients and 34 staff members.

**Method:** A naturalistic prospective observational design was chosen. Scoring categories were developed based on existing research literature in the fields of ID and autism, and psychiatry, respectively. Staff-patient communication sequences were video-recorded and 370 sequences (episodes) were scored. A second observer scored 10% of the sequences and reliability of measures was estimated by inter-rater agreement.

Staff measures; *response, joint attention, task sustenance, and emotional support*; were chosen based on existing papers on staff communication skills related to adults with ID and autism, and schizophrenia, respectively. The patient measures were designed to measure possible effects of the staff communication skills. The patient measures were: *disorganised behaviour, organised behaviour and initiatives*.

**Analyses:** The relative frequencies of relevant patient and staff behaviours *within episodes* were our chosen measures. For each of these episodes the relative observed frequencies (in percentages) of the relevant behaviours were computed. To examine inter-rater agreement, 37 episodes were randomly selected from the 370 episodes included in the study, and scored by a second observer. Inter-rater agreement on these relative frequencies was examined.

A more lenient criterion of agreement would be the “rank-profile ordering” of these relative frequencies. This means that although one observer could observe fewer instances of a particular behaviour than the other observer, he/she could still regard this as equally “dominant”. For example from paper II, table 3 it is obvious that the mean relative number of “meaningful answers” are lower for observer 2 (18.5) than for observer 1 (23.3). “Meaningful answer” is however the most prominent behaviour for both observers. Inter-rater agreement on these relative frequencies across episodes was computed as ordinary Spearman rank-order correlations.

**Results:** Even in this relatively small sample of observations, all but one of the predefined staff behaviour categories was observed. The analyses showed some slight disagreement on how often the different behaviours occurred as measured by mean frequencies, but substantial agreement on which behaviours occurred often/seldom as measured by rank-order correlations.

**Additional analyses:** While we were primarily interested in *the number of occurrences observed* it would be of interest to examine the agreement on *occurrence of particular behavioural acts*. To examine agreement at this level the observers must necessarily observe the same behavioural acts. To accomplish this, the second observer rescored the exact same behaviours observed and scored by the first observer. Inter-rater agreement was analysed by cross tabulating the two observers and computing Cohen’s Kappa. Results from these analyses were not presented in the previously published paper.

In tables 2.1 and 2.3 the observer 1 by observer 2 frequencies are tabulated. In tables 2.2 and 2.4 Kappa and percentage agreement are presented. Both Kappa and agreement were calculated from the overall tables (presented as ‘total’) and from sub tables organised as 2X2

tables with behaviours coded as present-not present. In the column ‘mean’ the mean Kappa and agreement measures calculated across these sub tables are presented.

Table 2.1. Staff agreement scores: Frequencies.

Observer 1	Observer 2						Total
	MR	JA	TS	ES	MLR	OF	
Meaningful response (MR)	27	0	1	1	0	0	29
Joint attention (JA)	8	34	0	1	0	2	45
Task sustenance (TS)	2	0	9	1	0	0	12
Emotional support (ES)	1	0	0	9	0	1	11
Meaningless response (MLR)	2	1	0	0	4	1	8
Other focus (OF)	0	1	0	0	1	15	17
Total	40	36	10	12	5	19	122

Table 2.2. Staff agreement scores: Kappa values and percentage agreement.

	Total	MR	JA	TS	ES	MLR	OF	Mean
Kappa	0.75	0.7	0.76	0.8	0.76	0.6	0.81	0.74
Agreement		107	109	118	117	117	116	
% agreement	0.8	0.88	0.89	0.97	0.96	0.96	0.95	0.93

Table 2.3. Patient agreement scores: Frequencies.

Observer 1	Observer 2			Total
	DOB	OB	PI	
Disorganised behaviour (DOB)	32	2	4	38
Organised behaviour (OB)	2	27	2	31
Patient initiative (PI)	11	8	62	81
Total	45	37	68	150

Table 2.4. Patient agreement scores: Kappa values and percentage agreement.

	Total	DOB	OB	PI	Mean
Kappa	0.69	0.68	0.73	0.67	0.69
Agreement		131	136	125	
% agreement	0.81	0.87	0.91	0.83	0.87

**Conclusions:** Even in this small sample, all predefined staff behaviours but one and all patient behaviours were observed. This supports the usability of the measures. Reliability of the measures was supported by substantial inter-rater agreement both for number of occurrences and for the occurrence of discrete behavioural acts. The reliability estimates indicated that some of the measures need further elaboration and refinement.

### 5.3. Paper III

Bakken, T.L., Eilertsen, D.E., Smeby, N.A., Martinsen, H. (2008) Effective communication related to psychotic disorganised behaviour in adults with intellectual disability and autism. *Nordic Journal of Nursing Research and clinical studies*, 88:28, 9-13.

**Background:** Adults with intellectual disability, autism, and schizophrenia display severe disorganisation, which affects their ability to communicate and to perform well-known tasks. They display an aggravated loss of ability to initiate interaction.

**Aim:** The aim was to examine whether a set of chosen staff communication skills coined “effective” could be shown to be really effective in decreasing psychotic disorganised behaviour and increasing initiatives in patients.

**Sample:** 370 episodes of staff-patient interaction were observed and scored. These episodes included 760 staff-patient transitions (from a total of 2546 staff and patient turns) from 4 patients and 34 staff members.

**Method:** The data analysed in this paper were the same as data analysed in paper II. Thirty-four staff members and four patients with intellectual disability, autism, and schizophrenia were included. Staff and patient interaction was video taped in natural settings.

**Analyses:** Data was analysed by a lag-sequential procedure. Contingency tables containing adjacent patient-staff or staff-patient observations were constructed. Co-variation between staff and patient behaviours were measured by phi-correlations and conditional probabilities. The data analysed in paper III was based on the scores from observer one only.

**Results:** When a staff member performed a communicative act theoretically construed as “effective”, the probability of organised patient behaviour was 0.74. When the communicative act was of the “non-effective” type, the probability of organised patient behaviour dropped to 0.55. The difference was clearly statistically significant ( $\chi^2=18.2$ ,  $df=1$ ,  $p<.0001$ ).

Table 3.2 is a corrected version of table 2 in paper III, and shows the conditional probabilities of initiatives, organised and disorganised behaviour dependent on type of staff communication. *Meaningful response* elicited most initiatives in the patient (20%). *Joint attention* elicited 9% initiatives and 56% organised behaviour. *Task sustenance* elicited 66% organised behaviour and only 1% patient initiatives. *Emotional support* elicited approximately the same amount of organised and disorganised behaviour. *Meaningless response* elicited 67% disorganised behaviour. *No joint attention* elicited approximately the same amount of organised and disorganised behaviour. *Meaningful response* elicited more



initiatives than *meaningless response*. A comparable difference was not found between joint attention and no joint attention.

Unfortunately, there was an error in table 3.2 as it was presented in paper 3. The error concerned the conditional probabilities of different patient behaviours dependent on *emotional support*. In addition the total number of observations was confusingly reported as 2546. This was the total number of turns observed. The number of observations analysed was however the total number of patient-staff transitions (n=760). These errors had no consequence for the main conclusion.

Table 3.2. Probabilities of initiatives, organised- and disorganised behaviour by type of staff communication.

	Initiatives	Organised behaviour	Disorganised Behaviour	Total
Meaningful response	20 %	31 %	50 %	239
Joint attention	9 %	56 %	35 %	298
Task sustenance	1 %	66 %	32 %	74
Emotional support	14 %	42 %	44 %	36
Meaningless response	14 %	19 %	67 %	43
No joint attention	6 %	44 %	50 %	70
Total	12 %	45 %	43 %	760

The heading of Table 4 in paper III may be misleading, as the results presented in table 4 show the relationship, calculated by phi-correlations, between subcategories of staff behaviour and patient “turns”. An updated table is presented below as table 3.4. As in table 3.2, the results were based on staff-patient transitions (N = 760, in a total of 2546 turns). The results support the results of the analyses presented in table 2. For example, *meaningful answer* was positively correlated with both organised and disorganised patient behaviour, and initiatives. Both attention-directed initiatives and attention-directed directives (which are commonly used interventions), correlated positively with organised behaviour, and negatively with disorganised behaviour, but was negatively correlated with patient initiatives. *Task support* was positively correlated with organised behaviour, but negatively correlated with disorganised behaviour. With regard to the main staff category *emotional support, physical soothing* was positively correlated with disorganised behaviour.

Table 3.4. Relations between staff communicational skills and patient behaviour (n=760 transitions).

			Organised behaviour	Disorganised behaviour	Initiatives
Response	Meaningful response	Meaningful answer	.18**	.10	.29**
		Confirm choice	-	-	-
	Meaningless response	No response	.03	.00	.02
		Meaningless answer	-.16**	.13**	.11**
		Reject choice	-.04	.04	.02
Attention	Joint attention	Attention-directed initiative	.08*	-.06*	-.09*
		Attention-directed directive	.16	-.11**	-.15**
	Other focus	Outside att. area-initiative	-.02	.05	-.10**
		Outside att. area-directive	.04	-.03	-.06
		Lost attention	-.07	.08	-.04
Task sustenance		Physical limitation	.04	.01	-.07
		Task support	.14**	-.11**	-.11**
Emotional support		Confirms feeling	.01	-.04	.00
		Physical soothing	.07*	.11**	.07*
		Mirroring	-	-	-

\* p<.05, \*\* p<.01

### Additional analyses:

Work experience: The 34 participating staff members were divided into two groups; one with more than five years of experience (n=22) and one with 0-5 years of experience (n=12). Table 3.5 shows the mean probabilities of using different types of staff communication by experience. *Effective communication* was used significantly more often by staff members with more than five years of experience. For *meaningful response*, *task sustenance* and *no joint attention*, there were statistical significant differences between the groups. *Meaningful response* was most often performed by the most experienced staff, while, *task sustenance* and *no joint attention* was more often performed by the less experienced staff.

Table 3.5. Mean probabilities of using different types of communication by years of experience.

	0-5	>5	Sig.
Effective communication	0.60	0.72	0.03
Meaningful response	0.14	0.25	0.04
Joint attention	0.30	0.38	0.13
Task sustenance	0.17	0.07	0.01
Emotional support	0.03	0.06	0.25
Meaningless response	0.06	0.03	0.48
No joint attention	0.17	0.09	0.03

**Conclusions:** Staff communication skills coined “effective” elicited significantly more organised behaviour, than skills coined “non-effective”. The various staff communication skills investigated seemed, however, to have varying impact on patient behaviour. Task sustenance and joint attention seemed most effective in eliciting organised behaviour, while meaningful response was most effective with regard to patient initiatives. In this study it was not possible to show any clear effects of *meaningful response* and *emotional support*. The more experienced staff used significantly more of the “effective” communication strategies.

## 5.4. Paper IV

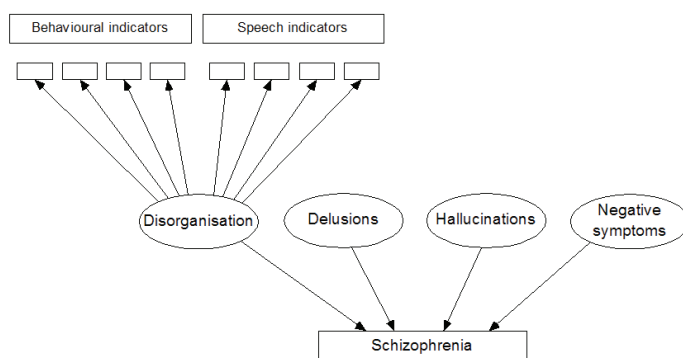
Bakken, T.L., D.E. Eilertsen, Smeby, N.A., Martinsen, H. (2008) The validity of disorganised behaviour as an indicator of psychosis in adults with autism and intellectual disability: a single case study. *Mental Health Aspects of Developmental Disabilities*, 28:2, 9-13.

**Background:** Schizophrenia in adults with intellectual disability and autism is rarely detected due to the patients' limited ability to report psychotic symptoms, and due to the complex task of differentiating between behavioural problems, schizophrenia and psychotic depression in these severely disturbed patients. Observable behavioural indicators are therefore needed in the assessment process.

**Aim:** In the present study, disorganised behaviour as an indicator of schizophrenia was investigated by examining the co-occurrence of behavioural disorganisation and disorganised speech in a patient with schizophrenia, autism and mild intellectual disability.

The rationale behind the design is visualised in figure 1 below.

Figure 1: Behavioural and speech indicators of disorganisation



**Sample:** Eighty-four sequences of interaction (episodes) were analysed.

**Method:** A single case design was chosen. One female patient aged forty-six with intellectual disability, autism and schizophrenia and 14 staff members participated in the study. The female patient was the only available schizophrenic patient with intellectual disability who was also able to speak well enough for the co-occurrence of disorganised speech and disorganised behaviour to be assessed. Patient-staff interaction sequences in natural settings were video-taped. Eighty-four episodes were rated for disorganised speech and disorganised behaviour, as “present” or “not present”. For analyses of inter-rater agreement, 40 of the

episodes were scored by a second observer for disorganised behaviour, and all 84 episodes were scored for disorganised speech.

**Analyses:** Observer agreement for 40 episodes was calculated by Cohen's Kappa. Differences in occurrence of disorganised behaviour given disorganised speech, was calculated in contingency tables. These analyses were based on the 84 episodes scored by observer one only.

**Results:** The results showed a significant relationship between occurrences of disorganised speech and disorganised behaviour. There was a significantly higher probability of disorganised behaviour in episodes with disorganised speech. Unfortunately, a total number of 85 instead of 84 observations were erroneously used in the contingency table presented in paper IV. This led to a slight decimal error of no significance for the conclusions in the reported figures. A corrected table is presented below.

Table 4.2. Probabilities of disorganised behaviour by disorganised speech (from 84 episodes)

Disorganised Speech	Disorganised Behaviour				Total
	Not present		Present		
Not present	7	.58	16	.22	23
Present	5	.42	56	.78	61
Total	12		72		84

Table 4.2 shows the relationship between disorganised speech and disorganised behaviour. The conditional probability of presence of disorganised behaviour contingent upon presence of disorganised speech was .78. In comparison, a conditional probability of .42 was found when disorganized speech was not present. The phi-correlation was .28. The difference was statistically significant ( $\chi^2=6.75$ ,  $df=1$ ,  $p<0.009$ ). As one cell had a low expected frequency, a Yate's corrected chi-square test was applied. The difference was even then statistically significant ( $\chi^2=5.05$ ,  $df=1$ ,  $p<0.03$ ). Co-occurrence of disorganised speech and disorganised behaviour was found in 63 (75%) of the episodes.

There was also a misprint in Table 3 in Paper IV. The difference in conditional probability of *derailment* was reported to have a Fisher's exact p-value of .05. The correct figure was .52. Thus, of the measures *Incoherence*, *Derailment*, and *Pressure of speech*, only *Incoherence* was found to be significantly related to disorganised behaviour.

**Conclusions:** The statistically significant relationship between disorganised speech and disorganised behaviour found in the present study supports a hypothesis of a general concurrence of the two. Thus, some support is given to the supposition that disorganised

speech and disorganised behaviour may reflect an underlying common factor. The results from this study also lend further support to behavioural disorganisation as a valid indicator of schizophrenia in people with autism and ID.

## 6. DISCUSSION

### ***6.1 Behavioural disorganisation as an indicator of schizophrenia (research question 1)***

There are two main findings which support that disorganised behaviour may be regarded as an indicator of schizophrenia. Firstly, people with schizophrenia show more disorganised behaviour than both people with plain autism and patients with non-psychotic psychiatric disorders. Secondly, there is a tendency that behavioural disorganisation occurs concurrently with disorganised speech. When disorganised speech and disorganised behaviour occur at the same time, based on a varying presence of symptoms, it supports that behavioural disorganisation may be used as an equivalent to speech disorganisation; both reflecting an underlying common factor. Since disorganised speech often is understood as a manifestation of thought disorder, this may be an obvious candidate when searching for a measure of this underlying common factor. The relation between disorganised speech and disorganised behaviour is further supported through the assessment of the people afflicted with schizophrenia. The majority of the patients (7 out of 8) with disorganised behaviour show a variety of concurrent schizophrenic symptoms, including disorganised speech and also severe impaired global functioning, hallucinatory behaviour, and negative symptoms. From a practical view the important finding is that observers by using the proposed instruments are able to implicitly detect the same key features of disorganisation; splintering, derailment, incoherence, and sequencing problems, in behaviour as well as in speech.

Behavioural disorganisation was observed both by observers that were untrained in observation of psychiatric symptoms (family and residential caregivers, mostly), and trained health care professionals, working with in-patients with ID, autism and additional psychiatric symptoms. Both kinds of observers showed high agreement on occurrences of behavioural disorganisation.

The highest observer agreement was observed for measures of disorganised speech. This is not surprising, as in most cases it is easier to agree on verbal statements, than on behavioural acts, especially since the psychiatric assessment tradition related to schizophrenia has been more focused on reportable symptoms than on observable indicators. Behavioural disorganisation could be reliably detected both by trained and untrained observers.

## **6.2 A tool for observation of staff communicative skills (research question 2)**

The theoretically defined measure effective communication can be used in observation of communicative skills of staff working with schizophrenic patients. Effective communication is comprised of four main categories of communication strategies and a total of 15 subcategories describing specific communication skills, and all but one of these subcategories (mirroring) were scored.

Staff communication could be observed with satisfactory reliability when all staff categories were taken together. A satisfactory reliability was also found for the four main categories.

All but one of the predefined sub-categories of communication skills comprised by effective communication was observed. This seems to reflect that they were regularly used by the staff members. It probably also shows that the staff had sufficient knowledge of their patients to be able to communicate meaningfully during daily routines.

Confirm feeling and confirm choice, which are well known and commonly used interventions in psychiatric care, occurred relatively seldom. This is, however, not surprising, since both these interventions are difficult to perform non-verbally. Non-verbal interventions are, of course, clearly indicated and natural to use in interaction with patients who have limited speaking skills. Also 'no response' occurred relatively seldom. This may partly be due to observational problems. As often recognized in observational studies, it is more difficult to perceive and be able to observe lack of expected responses than occurrences of specific predefined responses.

Effective communication is a theoretical term that refers to communication strategies meant to facilitate positive patient behaviour and interaction between patients and staff. The intention that the main categories should include meaningful response, attention sustenance, task sustenance and emotional support, surely reflect the theoretical bias of both the candidate and the specialised psychiatric hospital unit where the patients belonged. But the view that these communication strategies represent positive contributions to social interaction is hardly controversial. It is a common view both in the general social interaction literature and in the field of psychiatric nursing that being responsive and responding meaningfully, making it easier for the partner to sustain his/her attention, helping the partner to proceed with the task



he/she is performing, and giving emotional support have a positive effect on social interaction.

### ***6.3 Does “effective communication” decrease disorganized behaviour and increase initiatives? (research question 3)***

The hypothesis that “effective communication” decreases disorganised behaviour was supported when all four main categories defined as “effective” was taken together (hypothesis I). The conditional probability of organised behaviour was significantly higher following “effective” staff communication than it was following so-called “non-effective” staff communication. Thus, it seems that the kind of communication strategies coined “effective” truly tended to decrease disorganised behaviour.

The effect on disorganised behaviour varied, however, between the four main categories of “effective communication”. The hypothesis was that they all should be linked to lower probability of disorganised behaviour (hypothesis II), while “non-effective communication” should elicit higher probability of disorganised behaviour (hypothesis III). We found, however, a higher conditional probability of organised than disorganised behaviour only for two of them: task sustenance and joint attention. In accordance with the hypotheses joint attention and task sustenance seems to influence more organised behaviour in the patients. No such effect was found with regard to meaningful response and emotional support. Emotional support elicited approximately the same amount of organised and disorganised behaviour, while meaningful response clearly had a higher probability of disorganised than of organised behaviour. A possible explanation of this finding may be that these two categories are not properly understood and thus not perceived as meaningful by the patients, while they nevertheless appear to be meaningful and supportive in the eyes of the staff and the coders.

A comparison of meaningful response with its “non-effective” counterpart meaningless response gives, however, some support to hypothesis II also for this category. The probability of meaningful response being followed by organised behaviour was higher and by disorganised behaviour lower, than for meaningless response. Following answers meaninglessly, it was approximately three times more likely that the patients showed disorganised than organised behaviour. Generally, also the effects of the supposedly “non-effective” categories on disorganised behaviour and initiatives differed and varied between

the categories. When the staff members initiated social interaction without trying at the same time to achieve joint attention – i.e. giving directives or communicating outside the patient's field of attention - approximately the same likelihood was found for disorganised and organised behaviour. Task sustenance seems to be the most effective way of eliciting organised behaviour in the patients.

The various communication strategies also had varying impact on the amount of initiatives shown by the patients. In line with the hypothesised effects, meaningful response and emotional support seem to have a positive impact. These two main categories of "effective communication" had the highest probabilities of eliciting initiatives from the patients, and meaningful response was linked with a higher probability of patient initiative than meaningless response. Contrary to the hypothesis, however, task sustenance seems to be linked to a decrease in initiative, since it elicits a very low probability of initiative by the patients. In spite of its positive relation to organised behaviour, task sustenance thus seems to have a negative effect on patient initiatives. The communication strategies used by the staff seem to affect patient initiative and organisation of patient behaviour in different ways. Task sustenance and joint attention seemed most effective in eliciting organised behaviour, while meaningful response was most effective with regard to patient initiatives.

The hypothesis that the staff's behaviour should be less influenced by the patient's behaviour than vice versa was mostly supported. A notable exception was, however, found for initiatives taken by the patients, which are the only patient behaviour measures that seem to influence the behaviour of staff members. When the pattern of interaction between the staff and the patients is considered, it seems possible that a transactional chain may be formed. It seems possible that the staff members answering the patient's initiative may influence the patients to initiate interaction with the staff more often.

Support was given to the hypothesis that the more experienced staff members communicated "effectively" more often than the inexperienced staff members. A rather unexpected finding was, however, that less experienced staff performed task sustenance more often than the more experienced. A possible interpretation of this finding is that the more experienced staff members may have a more "passive" communication style, which stimulates initiatives from patients by making room for patient-initiated activity. Earlier studies of staff members' communication with psychiatric patients lend some support to this view (Bakken and Smebye, 2004).

## 6.4. Strengths and limitations

As this is a pilot study, there are limitations concerning aspects of validity.

Some of the categories in our measures of staff behaviour did not work very well. For *staff responses* there was low observer agreement and small effects on patient disorganised behaviour were evident. The response category, *no response*, was scored quite infrequently. The problems concerning measures of staff responses may have been reduced if the scorers had been trained in the patient's communicational styles, mainly their idiosyncratic ways of initiating contact and responding. These categories need thorough elaboration in a replication study.

In measures of patient behaviour, *sequencing problems* were not included. Sequencing problems seem to be relatively easy to observe once features are thoroughly described. It is also found to be a core feature of disorganised behaviour. To include sequencing problems as indicators of disorganised behaviour would have strengthened the staff communication study. Such indicators should be included in a replication study.

Data was scored as present/not present. Rating on a four-point scale could possibly have generated more accurate results. A more nuanced scale should be examined in a replication study.

The limited number of observations is perhaps the most serious limitation of the present study. A limited number of patients in paper I and a limited number of observations of both staff and patient behaviour in the other papers, posed restrictions of internal validity by limiting possible analyses and making conclusions concerning correlations uncertain. Another limitation is the duration of the episodes. Few of the episodes analysed in papers II and III lasted for more than half of a minute and on average only approximately 7 "turns" within episodes were observed. Longer interaction sequences would have made more detailed analyses of sequential association possible. The short interaction sequences do however reflect the "communicational style" of these patients and it may be questioned if it would have been possible to find significantly longer interaction sequences in *any* study of this group of patients.

The limited number of patients participating in studies II, III and IV also limits generalisation of conclusions. In paper IV generalisations are based on observations of only one patient and our conclusions will need to be corroborated in further studies focusing on the relationship between speech and behaviour disorganisation.

Interpretations of results are also limited by the non-existence of relevant comparison data and base rates on patient behaviour.

One strength of the present study is that we were quite certain that the patients included belonged to the relevant population. The patients were chosen because of their prominent symptoms of schizophrenia and clinically diagnosed according to DSM-IV/ ICD-10 criteria. The diagnostic assessment was conducted by experienced clinicians prior to the present project (see 4.2). Also, none of the instruments studied were used for diagnosis and there is no obvious measurement dependency between the clinically assessed psychiatric diagnoses and the detailed descriptions of features of behavioural disorganisation presented in this thesis. This is important, as it precludes circular reasoning.

One other strength of the present study is that observations were conducted and measures were developed and examined in natural settings that are clinically relevant. The observers, both trained and un-trained, were representative of observers that will use these instruments in future practice. The clinical setting was a special psychiatric unit with relatively stable staff and it can be assumed that staff members were socialised in the same tradition of psychiatric care for intellectually disabled patients. This reduced irrelevant variation due to settings and observers.

Other strengths of the present study were connected to the thorough search needed for accurate definitions of features of disorganisation in patients with impaired language skills. As there is no available research on staff communication related to patients with multiple diagnoses the search for principles of recommended staff communication was conducted within two separate disciplines: in the field of care for intellectually disabled adults and in the field of psychiatric care. This process itself led to a broader understanding of the actual phenomena studied and this is reflected in the measures developed – both the PAC and the instruments for observation of patient and staff behaviour.

## 7. CONCLUSIONS AND CLINICAL IMPLICATIONS

To our knowledge, this is the first study examining behavioural disorganisation as an aspect of schizophrenia in patients with multiple diagnoses of schizophrenia, intellectual disability and autism.

The study supports the use of signs of behavioural disorganisation as indicators of schizophrenia in this group of patients. Behavioural disorganisation can be seen as an equivalent to disorganised speech, which is understood as a manifestation of thought disorder. The results were consistent with the supposition that both disorganised behaviour and disorganised speech reflect an underlying thought disorder in schizophrenia.

The thesis thereby represents a needed correction on the common assumption within the field - that people with autism show disordered thinking in other ways than people with normal language skills. On the contrary, the disorganised behaviour of people with autism and ID may be described similarly as in people without cognitive impairments.

Results demonstrate that it is possible to develop measures based on observable behavioural criteria that may prove useful for detection and monitoring of schizophrenia in this group of patients.

It was also demonstrated that communication skills of intellectual disability staff can be monitored and evaluated. The chosen method of observation is however time-consuming and requires that observers are trained to evaluate patient behaviour and staff communication.

The communication skills investigated had varying impact on disorganised behaviour and initiatives. The term *effective communication* with regard to disorganised behaviour seems to include staff performing joint attention and task sustenance. *Effective communication* with regard to eliciting initiatives from the patient seems to include that staff is responding meaningfully to the patient and providing sufficient emotional support.

## **Clinical implications**

Accurate diagnoses of schizophrenia in intellectually disabled patients with autism make it possible to provide correct medical and psychosocial interventions. It is, however, difficult to distinguish schizophrenia from other severe psychiatric disorders. To differentiate schizophrenia from affective psychosis is, for example, a challenging task. Patients suffering from these disorders are often in an agitated state (Glenn, Bihm, and Lammers 2003; Sovner and Hurely, 1983).

When considering whether a person is suffering from schizophrenia, two out of five core symptoms must be present according to DSM-IV (APA, 1994). Delusions will most often not be reported. Hallucinations and disorganised speech are rarely detected in individuals with impaired language skills, and when observed, these observations alone are not sufficient indicators of a psychotic disorder (Hurley, 1996; Lee et al., 2003). When psychosis is suspected, behavioural disorganisation may be a favourable starting point in case identification. However, disorganisation may show up for instance when patient are experiencing anxiety attacks, or suffer from long-standing pain or other medical conditions. It is therefore of vital importance to assess whether behavioural disorganisation is present concurrent with other core symptoms of schizophrenia. If so, behavioural disorganisation may be attributed to a psychotic condition.

Availability of behavioural indicators of disorganisation will facilitate the clinically important task of differentiating between schizophrenia and other conditions –for example affective psychosis.

In the present study behavioural indicators of disorganisation were proposed and reliability and validity were supported. We also proposed observational methods and criteria for effective staff communication which may be useful both in identification of schizophrenia in patients, for staff training/ education, and for evaluation of therapeutic interventions.

Besides the obvious need for behavioural observations in clinical settings, our clinical experience underpins third-party information as important in the diagnostic process. When schizophrenia is suspected, the clinician will have to interview relatives and professional caregivers about the defined features of behavioural disorganisation; keeping idiosyncratic indicators in mind. Such an interview will be difficult to execute without asking about defined behavioural symptoms of schizophrenia. This includes disorganisation manifested by gross

disorientation, sequencing problems, task derailment, aggravated social withdrawal, bizarre motor activity, and unexpected aggression:

“Clare” is severely intellectually disabled and has autism, usually using and understanding the meaning of approximately 20-30 words. In retrospect, it seems that she has experienced at least three episodes of schizophrenia. However, she was not diagnosed as suffering from schizophrenia before the last episode. She was referred to psychiatric assessment as she displayed sleeplessness and lost about 25% body weight. Her verbal language disappeared. She both attacked persons without early signs of aggression and destroyed things in the environment. This challenging behaviour was for the most part associated with anxiety attacks. Delusions or hallucinations were not reported and difficult to assess. The staff observed behaviour suspected to be “auditory hallucinatory behaviour” (steady holding her ears, and she used to complain about “hurt in the ear” without otitis or other ear trouble). At the same time she was screaming.

If the problems described above encompassed all available information about Clare’s condition, we would lack clues for identifying the origin of her problems, and how to supply the right treatment and care. A closer look revealed important additional information:

This organised behaviour was observed and assessed as severe during the acute phase, but was still the most prominent sign of psychosis for about four to five months. Clare displayed distorted ability of sequencing during almost all activities through the day. She seemed to hesitate and frequently stop during all activities, also when walking. She stopped, turned around, went back a couple of steps, turned around again, and took some steps forward. After a few steps she stopped again. She seemed confused in most settings and was not able to keep her attention focused for more than a few seconds. She used to eat paper napkins.

The detailed description in the latter passage, when added to the information provided above, provides additional information relevant for both assessment and treatment. The case files describe the stress symptoms, but contained no references to a possible psychosis.

Members of the staff did not focus on, and were not able to describe disorganised behaviour, until the interviewer listed the defining criteria. This negligence of behavioural disorganisation is common. As disorganised behaviour is not a commonly used indicator of non-affective psychosis, it is for the most part not highlighted or focused upon during the assessment procedure.

Individuals with autism are characterized by idiosyncratic speech and behaviour, which in most cases probably will increase when the patient is psychotic. This emphasizes the need for profound knowledge of the patients' idiosyncratic ways of behaviour, additional to the use of thoroughly defined behavioural indicators, as suggested in this thesis. If professionals don't know the patient well, it might be difficult to judge if the patient is disorganised or not. An example: When "Peter" who is severely ID and autistic, and lives in a community based residence, is heading for the coffee table, he has a grand menu of touching doors and the TV, bending his knees twice etc, before he enters the coffee table. This behaviour is his "normal" way of behaving, but might appear as severely confused, if this complex ritual is unknown to the observer.

A structured instrument as proposed in PAC may be useful both as a tool for collection of relevant information on behavioural indicators, and for direction of focus to behaviour relevant for diagnosis and interventions.

Initially, before the start of the project, it was believed that an entirely different set of criteria was needed to recognize patients with schizophrenia within the sub-group of persons with severe ID and autism. However, criteria used for assessment in the normal population also worked for these patients. Furthermore, similar kinds of treatment were shown to be efficient in the autism and severe intellectually disabled patients sub-group as in other psychotic patients.

When behavioural criteria are used for diagnosis, prevalence and incidence might be affected. This will hopefully contribute to a reduction in the large variance found in prevalence and incidence of severe mental illness in the autism population (For a documentation of the large variance in prevalence and incidence figures, see Howlin, 2003).

Psychotic patients live in a chaotic world. They may be disorganised and socially withdrawn to such a degree that staff members can hardly reach them. Severely disturbed adults with schizophrenia, autism and ID do not often have the capacity to act like an equal



communication partner. They are extremely hard to understand and communicate with. At some moments neither themselves, nor their communication partners seem to have any clear opinions about their wants or needs. Thus, improving staff communication is important. The results from the present project support that different ways of communicating with the patients influence disorganisation and initiation of social interaction with staff – both positively and negatively. It is important to know how the patients are influenced by the communication of the staff members; for example that task support and joint attention is the preferred communication strategy, when the patient is severely disorganised.

Research on milieu therapy in psychiatric care for patients with psychosis has in Norway been especially focused on ward atmosphere (emotional climate) in psychiatric hospital wards (Friis, 1986; Røssberg, 2005). The ward atmosphere for hospitalised patients with psychosis is recommended to be characterized by a milieu with a high level of support, practical orientation, order and organisation, and a low level of anger and aggression (Friis, 1986) and if these criteria are met, probably also a high level of involvement and a low level of staff control (Røssberg, 2005). The results from the present study indicate that the findings related to research on ward atmosphere are also relevant for patients with severely impaired language and intellectual skills. Support and practical orientation can be understood as equivalence to task sustenance, which was the staff attitude that had the most positive impact on the level of disorganised behaviour in the staff communication study. On a more global level, the present findings correspond with what is found in research on psychosocial factors impacting psychotic symptoms in neurotypical persons; – that the surroundings and the way milieu therapists form the milieu and communicate with patients, impact patient outcome positively. The present study showed that when staff responds presumably meaningfully, the patient does not become predominantly organised. It might be that the patient feels unease and stress when staff is responding, and the patient might not understand. This result might be interpreted in line with research on communication of carers, especially in families. EE (expressed emotion) is such a factor. Subcategories of EE found predictive of symptomatic exacerbation or relapse, are criticism, hostility and over-involvement (Marom et al, 2005; Bebbington and Kuipers, 1994). What has been found is that patients are very sensitive to perception of criticism (Smeby, 1998). The knowledge of EE has resulted in psychosocial treatment programs reducing the EE factor in the participants (Hogarty et al., 1991, McFarlane et al., 2003). Such treatment programs might be adapted to families including members with ID and psychosis.

## 8. APPENDIX

### Psychopathology in Autism Checklist (PAC): Distress Symptoms and Psychosis items

Distress symptoms	Psychosis
Passivity	* Derails within conversation or task
Less initiative	* Attacks staff or others unexpectedly
Sleep problems	* Gross disorientation
Executive problems	Delusions
Crying	Threatening behaviour
Avoiding social settings	Rapid mood fluctuations
Irritability	Auditory hallucinations
Repetitive behaviours	Hallucinatory behaviour
Self-injury	* Lack sense of orientation in known areas
Despaired by self-injury	* Gross disorientation within social interaction
Communicates less	
Breaking items	
Obsessed by confirmation	
Violent behaviour	
Complaints about pain	
Restlessness	
Anger	
Compulsory behaviour	

All items in the PAC were rated by two independent observers, on a scale from 1- 4 (1 = no problem, 4 = severe problem).

\* = Items of behavioural disorganisation

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# Observing communication skills in staff interacting with adults suffering from intellectual disability, autism and schizophrenia

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## ABSTRACT

**Background:** Related to nursing, co-morbidity of intellectual disability (ID), autism and mental health problems, generate a need for integrated knowledge from both intellectual disability nursing and psychiatric nursing.

**Aim:** The aim of the current paper is to examine the reliability of an instrument designed for observing communication skills in professionals caring for patients with intellectual disability, autism and schizophrenia.

**Procedure:** A naturalistic prospective observational design was chosen. Scoring categories were developed, staff and patient communications were video-recorded and then scored. Reliability was estimated by inter-rater agreement.

**Results:** Across 370 sequences of interaction, all categories except one were observed. Inter-rater agreement on the observational categories was high.

**Conclusion:** The instrument worked as expected according to both observer agreement and presence of staff communication skills.

**KEYWORDS:** communication skills, autism, intellectual disability, schizophrenia, disorganised behaviour.

## Introduction

The prevalence of psychiatric disorders is assumed to be higher among individuals with intellectual disability and autism than in the general population (1,2,3,4,5). Co-morbidity of intellectual disability (ID), autism and severe mental health problems like psychosis generate a need for integrated knowledge from both intellectual disability nursing and psychiatric nursing.

The essential features for *intellectual disability* (ID) are sub-average general intellectual functioning, defined by intelligence quotients (IQ) of 70 or below (6). The cognitive impairments of low IQ are accompanied by impaired adaptive functioning of communication, self-care and social skills. Intellectual disability is normally assessed in four levels; mild, moderate, severe and profound.

Individuals with autism display a wide range of cognitive impairments (7,8), which include restricted ability of abstraction, introspection, understanding of other individuals, and the ability of sharing attention ('joint attention'). Staffs must therefore aim at clarity and a high level of contextual attachment in their communication (7,8). The patients' idiosyncratic communication and behavioural acts require that the communicating partner know the patient well enough to integrate both contextual and situational knowledge (7, 9).

Patients with schizophrenia are found to present severely impaired communication skills (10).

The main symptoms of schizophrenia are delusions, hallucinations, disorganisation and negative symptoms (6). Patients with ID do not have the full ability to report delusions and hallucinations. Behavioural disorganisation is observable and is therefore of certain interest. It can be described by the following behaviours: derailment, aimlessness, sequencing problems and disorientation (11). Patients who usually have (some) verbal skills will display incoherent and impoverished speech (12). Patients who are in a psychotic chaos need protection and support (13). Responding meaningful and emotional support are emphasised as core factors in psychiatric nursing (14, 15).

The patients with ID, autism and schizophrenia will in the acute phase appear severely disorganised (12,16). They will not master their role as an equal communicating partner because they lack the cognitive, emotional and social capacity required to understand the other participant (17). The staff ought to master and be aware of the particu-

lar ways each and every patient communicates because adults with ID and autism are exceptionally different even though they share core features of impaired communication.

These severely disturbed patients will need of a wholly compensatory nursing system (18). The patients' level of self-care is at a minimum, which will require continuous guidance and help from staff. A wholly compensatory system requires asymmetric communication with staff as the adjusting partner (19).

In learning disability nursing, there is still a need for research and theory development (20). Still, there is a whole body of research including staff communication with intellectually disabled persons. Especially adaptation to the clients' communication level and use of non-verbal communicative acts (gestures, augmentation devices etc) are emphasised as fundamental staff communication skills (21). Research papers focusing staff communication emphasise the importance of effective communication, but few have examined specific skills (17,22,23,24,25,26,27,28, 29).

Theory and research aimed especially towards psychotic patients with intellectual disability is sparse and still include no articles on treatment, milieu therapy or nursing.

A literature search in the Medline, Cihnal and Psych-info bases gave a sparse result. The use of the key words *communication + intellectual disability + mental health* revealed less than 10 relevant papers. A search for *psychiatric / mental health nursing + intellectual disability* gave three relevant hits. Altogether 25 papers from the search are referenced here.

The aim of the current study is to examine the reliability of an instrument designed for observing communication skills in staffs caring for patients with ID, autism and schizophrenia, and examine whether this set of staff communication skills is effective in treatment. If the chosen communicative skills prove to be effective, it will be of vital importance related to both treatment and training of staff.

## Material and methods

A prospective observational design is chosen. Data is collected in naturalistic settings of interaction between patients and staff (30, 31, 32, 33).

The study was carried out in an in-patient unit treating ID patients



with psychiatric disorders. This unit has over a ten-year period emphasised on ward atmosphere and a low expressed emotion milieu therapy (34). A dyadic frame was chosen for data collection.

## Participants

### Staff

A random sample of 34 staffs (nurses and nurse's aids) was recruited from the special unit (34). A random sample of staff was secured by a procedure where the first author arrived at ward unannounced at different times during the day within a six months period.

The staffs were invited to participate on a voluntary basis and their confidentiality was guaranteed. There had been thorough information about the project prior to the data collection. The work experience of staffs was a mean of 5.6 years (range: 10 months – 16 years).

### Patients

A selected sample of 4 patients was recruited. Inclusion criteria were verified diagnoses of intellectual disability, autism and schizophrenia. The patients were mildly- severely intellectually disabled, between 31 and 52 years. They were behaviourally disorganised and showed derailment, disorientation, aimlessness and problems of task sequencing. Three patients showed disorganised language. The also showed social withdrawal and severely impaired global functioning. The patients' psychotic symptoms were measured previous to the video recording, using the Positive and Negative Syndrome Scale, PANSS (36). PANSS' scores indicated active psychotic symptoms in the four patients. The four patients were not in the most acute phase during the video-recording period.

Exclusion criteria were epilepsy or other neurological disorders associated with psychotic features, i.e., hallucinations or disorientation (35). The patients have all been admitted to psychiatric hospitalisation for between one and twelve years (mean 8.5 years).

## Conceptual framework for the chosen measures

As there are few existing recommendations for staff communication related to patients with both intellectual disability and psychiatric problems, communication skills were chosen for the present study on the background of a broad search for existing research in respectively the intellectual disability and the psychiatric clinical fields.

## Staff measures

Altogether four main categories of staff communication skills were chosen for examination; *response*, *attention sustenance*, *task sustenance*, *emotional support*.

*Responsiveness* is found to be particular important towards adults with psychotic symptoms in general (37,38). *Meaningful response* is found to be a core dimension of communication in therapeutic settings (31). Responses should be concrete and nonverbally contextually relevant due to both cognitive impairment and disorganisation (17,21,37,39).

To elicit and respond to the patients' initiatives is particularly important when interacting with adults with autism and ID. Studies of turn-taking in parent-infant communication have found the infant to be far more active than earlier assumed, by learning from the mothers' responses, rather than modeling the mothers' acts (40,41).

*Attention deficits* regarded the ability to achieve *joint attention* are found to be present in people with autism from early childhood (8,42). Shared focus implies concatenation of initiatives and answers from both caretaker and patient. (43). Attention deficits increase with additional psychotic symptoms. Due to their communicational and social difficulties, adults with autism will have difficulties with social interaction (44).

The severe cognitive disorganisation of people with active psychotic symptoms will normally cause them to derail easily (45,46). These symptoms will appear as especially prominent in psychotic patients with ID. Trained, well-known tasks will be performed inaccurate or not at all. The patient will be in need of practical task support. When the patient has impaired impulse regulation or is aggressive, a highly structured environment is inducted, and limit setting might be necessary. (12,16). However, limit setting must be non-affective and conducted without criticism (47).

Emotional support has been reported to have a significantly positive impact on both physical and emotional problems (48,49,50,51). When the patients experience that their feelings are seen and accepted, they may be able to act according to their own emotions in daily life. Adults with ID and autism tend to be emotionally unstable and vulnerable (38,40). The emphasis on emotional support is traditionally associated with psychodynamic tradition (52) and can be transferred into techniques of interpreting behaviours/facial expressions and

Table 1: Staff scoring categories

MAIN CATEGORIES		SUB CATEGORIES
Response	Meaningful response	<i>Meaningful answer:</i> staff's response refers to patient's last turn. Response is concrete / nonverbal language is adjusted to message
		<i>Confirm choice:</i> staff approves patient's choice, verbally or non-verbally
	Meaningless response	<i>No response:</i> response to patient's initiative is missing
		<i>Meaningless answer:</i> it is obvious that patient cannot understand staffs' replay
Attention sustenance	Joint attention	<i>Reject choice:</i> patient's choice is rejected by staff disapproving, verbally, or non-verbally
		<i>Attention-directed initiative:</i> staff initiates communication inside the field of the patients' attention (the visual field, in which the patient is able to focus objects or people)
		<i>Attention-directed directive:</i> staff gives directive inside the field of the patients' attention
	Other focus	<i>Outside attention area-initiatives:</i> staff talks to patient <i>outside</i> field of the patients' attention
		<i>Outside attention area- directive:</i> staff gives directive <i>outside</i> field of the patients' attention
		<i>Lost attention:</i> staff's attention is drawn to object / person other than patient
Task sustenance	Task sustenance	<i>Physical limitation:</i> staff attempts to prevent patient from derailment from where he is
		<i>Task support:</i> staff attempts to start, continue or complete patient derailing from ongoing task
		<i>Adjust tempo:</i> staff waits for patient or attempts to catch up with patient
		<i>Prepare for activity:</i> staff prepares for activity by finding needed items etc
Emotional support	Emotional support	<i>Confirm feeling:</i> staff attempts to interpret patient's present feelings (anger, joy, or sadness)
		<i>Physical soothing:</i> staff comforts patient by touch
		<i>Mirroring:</i> staff imitates the patient's actions
		<i>Adjust Emotional level:</i> staff has a stable emotional level when interacting
	'Other'	Not covered by categories above



respond contingent to these expressions or behaviours, or imitate behaviour in the patient (53).

In order to examine the effects of the four groups of categories of staff communication, it would have been an advantage to construct negation to all four groups presented above. For the main categories *Response* and *Attention*, negation categories were constructed. However, the pilot study revealed that it was not possible to make negation categories for the main categories *Task sustenance* and *Emotional support*.

#### Patient measures

In order to examine influence from staff communication on psychotic symptoms in the patients, two domains of symptoms of schizophrenia were chosen for observation; *behavioural disorganisation* and *social withdrawal*. Behavioural disorganisation and social withdrawal are found to be core indicators of schizophrenia in adults with intellectual disability and autism (12,16).

Social withdrawal is also one of the characteristics of autism. Individuals with autism are known to communicate in atypical ways (7). The staffs' ability of recognising initiatives from the patient, who are severely socially withdrawn by both autism and schizophrenia, will be of vital importance to get into interaction with these patients (17).

To be able to examine a possible effect from staff communication, the patients' symptoms were divided into respectively disorganised and organised behaviour. Initiatives from the patient are categorised as *organised behaviour*. The amount of initiatives from the patients will serve as an indicator of level of social withdrawal.

The amount of initiatives from the patients will be possible to examine according to how often the patient initiate interaction with staff.

Normally intelligent people for the most part speak when they contact others. Individuals with intellectual disability are known to contact others also by gaze, by physical initiative (e.g. lead by hand) or by gestures (31).

The level of disorganised behaviour will be possible to examine on 'turn' level (see below) by the categories described by Flaum and Schultz (11): derailment, aimlessness, sequencing problems and disorientation. Aimlessness is defined as *auto manipulation* or *self-destructiveness*, disorientation as *aimless wandering*.

A fundamental assumption in this study is that effective staff communication will influence psychotic behaviour in the patient in two ways; the patients will be less disorganised and will present more initiatives towards staff.

These hypotheses will be examined and discussed in part two of this paper.

#### Procedure

##### Pilot study

The categories were tested in a pilot study connected to counselling of staff in the actual psychiatric department, in a ward not a part of the main study.

The feed-back from these 14 sessions was compared to communication skills recommended in the literature and then adjusted until the categories were considered sufficient. The patient categories were elaborated after the pilot study.

##### Main study

Situations of interaction within a dyadic frame, naturally occurring during the day were chosen at random and recorded by videotape, e.g. meals, dressing, school lessons and working hours (32,33).

Observations were coded according to the measures presented above using an IT-based dialogue-skill analysing programme developed at the Norwegian Technical University in Trondheim, NTNU (more info on request to first author).

No instructions were given to staff prior to recording, except for the general information given about the study. All participating staffs were blind to the scoring categories. The video-records consist of 71 recordings, ranging from approximately 5 to 20 minutes. Altogether, these 71 recordings encompass 370 sequences of interaction.

Data collection is based on observation of staff communication and patient symptoms within sequences of interaction, interaction *episodes*. These observations on behavioural level are defined as 'turns'. Such an observational system based on turn-taking is widely used in psychological research (31,54). Observation of turn-taking is based on a coding system where all behaviours of interest for the actual study are

systematically defined prior to the observation and scoring (ibid).

Data are organised on two levels, episodes and turns. *Episodes* = sequences of interaction and *turns* = behavioural acts.

The total number of turns scored in episodes varied from 1 to 32 (mean of 6.9) turns per episode. A total of 370 episodes were scored, including 1169 caretaker turns and 1377 patient turns (2546).

#### Reliability

Reliability of data is estimated by observer agreement, a widely used method when observing behaviour (54,55).

Assessment of the patients' behaviour as «organised» or «disorganised» might be possible also if the observers do not know the patient well. Dressing might serve as an example. When the patient starts walking with his jeans half way up, it is obvious that the patient is derailing from task. To assess whether staff gives a meaningful response to an idiosyncratic utterance or initiative from the patient is far more complicated and require thoroughly personal knowledge about the patient.

Two experienced psychiatric nurses, who also know the four patients well were trained in the scoring categories by watching the video-recordings from the pilot study.

To acquire information on whether scorers defined behavioural turns in the same manner, the number and time code of occurrences of behavioural turns within sequences of interaction were not defined prior to scoring. Agreement was examined on the number of turns scor-

Table 2: Patient scoring categories

Main categories	Sub categories
Organised behaviour	<i>Targeted approach</i> : patient approaches target object
	<i>Targeted behaviour</i> : patient performs known activities correctly
	<i>Physical initiative</i> , i.e. takes staff by hand
	<i>Verbal initiative</i> : talks to staff
	<i>Gaze initiative</i>
	<i>Meaningful answer</i> : patient's answer or gesture is connected to caretaker's previous turn
Disorganised behaviour	<i>Follow directive</i> : patient follows directive
	<i>Repetitive behaviour</i>
	<i>Rocking</i>
	<i>Auto manipulation</i>
	<i>Aimless wandering</i>
	<i>Derailment</i>
	<i>Self-destructive behaviour</i>
	<i>Violent behaviour</i>
	<i>Crying / shouting</i>
	<i>Meaningless response, words or gesture</i>
'Other'	<i>Does not follow directive</i>
	Not covered by categories above

Further definitions of the categories used are available from the first author.



red in a certain way within each episode. In addition to scoring of turns, each scorer noted the exact time when the behaviour was observed. This made possible qualitative analyses of whether scorers actually observed significant behaviours the same way within each episode.

This procedure includes category-by-category agreement, which will make it possible to elaborate the scoring categories further.

### Ethical considerations

Permission to conduct the present study has been given by the following instances: the director of the hospital and the four families/guardians have been informed, and they approved. All staff gave their informed consent. One patient gave informed consent. The three others are not capable of giving consent. They were informed prior to all video-recordings about the recording. The Eastern Regional Ethical Board of Norway has given permission to record patients and caretakers using a video camera. All original data (videotapes) will be destroyed when the study is closed, as required by Norwegian law.

### Results

A total of 370 episodes encompassing 2546 communicative acts – 1169 staff communicative acts and 1377 patient behaviours – were observed.

### Observer agreement

For each scoring category, Table 3 shows the mean percentage of turns scored within 37 episodes by observers.

Inter-rater agreement between observers was computed for each observation category. Inter-rater agreement ( $r$  in Table 3) was computed as a correlation between the numbers of behaviours of a given category observed by two observers across 37 episodes (10% of all episodes). For most of the categories, there was high agreement about occurrence of the behaviours.

There was some disagreement regarding how often categories were observed – for example 'meaningful answer' was observed in 23.26% of the 37 episodes by observer 1, while the correspondent figure was 18.49% for observer 2.

The Spearman rank-order correlations between the two scorers on the relative distribution of scores (profile correlations of columns) are very high ( $r = .98$  for staff categories and  $r = .93$  for patient categories). This indicates that although there is some disagreement on how often different behaviours occur, the agreement on which behaviour occurs frequent or less frequent, is high.

### The staffs' scores

*Effective communication* and *Non-effective communication* are scored in 78% and 22% of the staff turns, respectively. The main categories *Meaningful response* has a high frequency (29%) compared to *meaningless response*, which has a low frequency (6%). *Meaningful answer* is the most scored subcategory.

*Joint attention* is scored twice as often as *other focus*, respectively 34% and 16%.

*Task sustenance* is scored quite often, 10%.

*Emotional support* is scored in few of the turns, 5%. The subcategory *imitating* is not scored at all. *Adjust emotional level* is scored in almost all interactions. *Confirm feeling* is almost not scored at all.

### Patients' scores

*Organised behaviour* occurs in 56% of all patient turns. Initiatives, verbal, physical, or by gaze, taken by patients, cover most organised behaviour. Activity behaviours, *walk towards target object* and *perform known activity correct*, also occur quite often. So do *meaningful answer* and *follow directive*.

*Disorganisation* occurs in the remaining patient turns. The subcategory *derailment* was scored most often. *Moving, apparently without target* is scored quite often.

Challenging behaviour, *self-destructive behaviour*, *violent behaviour*, is almost not scored. *Crying/shouting* is scored infrequently. So is *Meaningless response*. *Repetitive behaviour*, *rocking*, *auto manipulation* is scored infrequently.

### Discussion

An overall picture is that data indicate a highly satisfactory reliability.

In order to obtain sufficient specificity of each category, the scoring categories were constructed to be mutually exclusive and defined to avoid bias in the scoring process. The results on observer agreement indicated that some categories were not easily kept apart. Of the staff categories, *meaningless answer* and *outside attention-directed directive*, obtained  $r < .5$ , which is somewhat lower than desired. Of the patient categories, the category *targeted behaviour* obtained  $r < .5$ . These categories need to be elaborated further.

The small disagreement on number of occurrences within each interaction sequence was mainly due to one of the observers scoring certain behaviours as occurring more than once. The high inter-scorer agreement, the fact that all categories (except one) were used and the low occurrence of 'other' behaviour, lend support to the present method as reliable for assessment of staff-patient communication.

Regarding the definitions, most categories, both staff and patient

Table 3. Mean relative distributions of scores by two observers

Staff scores				Patient scores			
	Obs. 1	Obs. 2	$r$		Obs. 1	Obs. 2	$r$
Meaningful answer	23.26	18.49	.87	Targeted approach	15.26	8.55	.68
Confirm choice	0.23	0.88	–	Targeted behaviour	10.48	6.01	.46
No response	1.84	0.53	.70	Physical initiative	4.47	5.31	.93
Meaningless answer	6.58	7.84	.46	Gaze initiative	7.24	6.67	1.00
Attention-directed initiative	23.36	18.49	.77	Meaningful answer	12.22	12.99	.80
Attention-directed initiative	10.35	9.57	.89	Follow directive	7.02	7.02	1.00
Outside attention-directed initi.	11.18	16.54	.83	Repetitive behaviour	0.20	0.81	–
Outside attention-directed directive	1.84	3.16	.47	Rocking	1.32	2.85	.56
Lost attention	4.61	3.29	.81	Auto manipulation	0.10	0.53	–
Physical limitation	2.31	2.63	.68	Aimless wandering	12.50	15.13	.90
Task support	5.48	5.70	.90	Derailment	8.24	14.84	.80
Confirm feeling	1.05	1.05	–	Meaningless response	4.50	4.35	.95
Physical soothing	5.92	4.30	.62	Does not follow directive	0.10	0.10	–

$r$  = observer correlations across sequences of interactions (within behaviour category).

– = not computable, caused by few observations



categories seemed possible to keep apart, which is a fair result, related to the complexity of observing and assessing behaviour in a sample of such severely disturbed patients.

Regarding the occurrence of the defined scoring categories, the sub-categories are observed in a satisfactory number of occurrences. All except one of the staff categories (*imitating*) were scored. Both effective and non-effective communication skills are scored in a frequency that allows analysis of effects related to disorganised behaviour. All patient categories were scored. Variation in patients' behaviours ensures the task of evaluating staff communication as effective or not. Analysis of effect of staff communication skills will be presented and discussed in part two of this paper.

All in all it seem that the categories cover a broad spectrum of staff communication. The assessment instrument works as expected according to reliability criteria and proves that principles of communication can be transferred into observational categories. The instrument can prove to be favourable and adaptable when educating nurses within this field.

### Limitations of the study

The present study has limitations related both to methods and sampling.

Assessing communication of intellectually disabled and autistic adults with idiosyncratic speech and behaviour is complicated due to the fact that the scorers must know the subjects well enough to consider what is meaningful in the communication process. This is especially important when considering that there are additional difficulties when the patient is psychotic.

A second limitation is the sample size. The four patients are recruited because of the severity of their symptoms. The limited numbers of patients and the severity of their symptoms question the external validity. Variation in staff skills are secured both by the number of staff and of the number of episodes observed and assessed, though it might be argued that the staff constitute a rather homogenous group, as they work in the same department.

Further research of other samples of patients and staff is needed to validate the scoring categories presented in this study.

Accepted for publication 27.09.07

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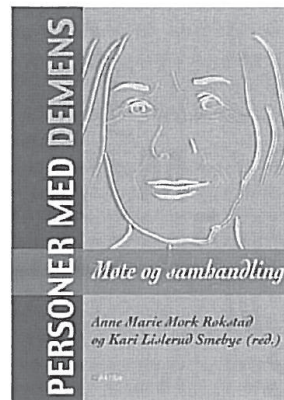
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# Effective communication related to psychotic disorganised behaviour in adults with intellectual disability and autism

Trine L. Bakken, RN, M.H. Sc. – Dag E. Eilertsen, senior IT engineer – Ina Aa. Smeby, RN, Ph.D. – Harald Martinsen, Psychologist, Professor

## ABSTRACT

**Background:** Adults with intellectual disability, autism, and psychotic symptoms display severe disorganisation, which affects their ability to communicate and to perform well-known tasks. They display an aggravated loss of ability to initiate interaction with their staff.

**Aims:** The aim was to examine whether a set of chosen staff communication skills was effective related to psychotic disorganised behaviour and initiatives in the patients.

**Materials and methods:** Three hundred and seventy sequences of dyadic staff and patient interactions were analysed. Thirty-four staff and four patients with intellectual disability, autism, and psychoses were included.

Staff and patient interaction was observed by video camera in the natural settings. Two independent observers scored each category. Data were analysed using contingency tables and the significance level was computed using Chi-square analysis.

**Results:** The probability of disorganised behaviour in the patients *decreases* significantly and the amount of initiatives *increases* significantly when the staff communicates effectively. The four main categories of staff communication have different effects upon the disorganised behaviour and initiatives from patients. Task sustenance was most effective on disorganised behaviour, whereas emotional support encouraged most patients' initiatives.

**KEYWORDS:** communication skills, autism, intellectual disability, schizophrenia, disorganised behaviour.

## Introduction

Staff communication in disability nursing may affect disorganised behaviour in psychotic adults with intellectual disability (ID) and autism.

The communication skills of disability staff is fundamentally important because the patients are impaired. Intellectual disability causes cognitive dysfunction and maladaptive skills. Persons with autism have little communication and interpersonal skills. This impaired ability to communicate and interpret surroundings is severely aggravated in ID persons with additional autistic and psychotic features. Persons with psychotic symptoms, ID, and autism display severely disorganised behaviour. The patient's disorganisation is manifested by derailment, gross confusion, and impoverished speech (1,2,3). Persons with autism are characterised by limited social skills and idiosyncratic social behaviour including relatively few initiatives (4).

The patients will display grossly disorganised behaviour during social interaction. Tasks that the patient normally performs well are no longer performed, or performed inaccurately. Behaviours that normally are linked together into purposeful chains are splintered into fragments and appear meaningless. The patient has difficulty coordinating motor, sensory, or cognitive processes. The patient will seem confused, uneasy, and restless. The amount of initiatives from the patient might be absent or prominently decreased.

The patient's lack of understanding causes frustration. Idiosyncratic speech and behaviour makes interacting even more complicated to understand and difficult to respond adequately to the patients' initiatives or behaviour. When combined together, advanced and complex communication skills will be vitally important when staff interact with these patients.

There is a fundamental assumption underlying psychiatric clinical work that a skilled and experienced therapist has positive impact on emotional disturbances in persons with mental disorders (5,6). The need for effective communication is acknowledged in disciplines such as psychology, psychiatry, education, and nursing (7). Communication is the basis for all social and professional interaction. Communication is herein defined as communicative acts between persons within a dyadic framework. The quality of social interaction is closely linked with the communication skills of the participants (8).

Effective communication has been proven to be efficacious when healthcare providers communicate well. It has also been reported that training increases the ability of effective communication in healthcare providers (9,10,11,12).

Communication training of disability staff is necessary due to the patient's complex condition. Training is mandatory because disability staff spend the majority of the day interacting with their clients (13). Effective communication has the potential to have a positive influence on behaviour throughout the day.

The present paper is part two of a study on effective staff communication related to severely disturbed patients. The first paper describes the process of defining suitable scoring categories to represent effective communication (14). These skills were tested empirically. The first paper addresses reliability. The observation categories were found to be reliable according to observer agreement and presence of preferred skills.

## Aim

The aim of this study is to examine the effects of staff communication when responding to disorganisation in adults with ID, autism, and psychotic symptoms.

## Variables

There are two variables that affect this study: disorganised behaviour and initiatives by the patient.

## Hypothesis

1. The chosen categories of communication will decrease disorganised behaviour in the patients.
2. The four categories of communication skills – *response*, *attention sustenance*, *task sustenance*, and *emotional support* – will independently decrease disorganised behaviour in the patients and increase their initiatives.
3. Non-effective communication will increase disorganised behaviour in the patient and decrease initiatives.
4. The staff's behaviour is less influenced by the patient's behaviour;

however, the patient's behaviour is greatly influenced by the staff's behaviour.

5. More experienced staff will communicate effectively more often than staff with less experience.

## Methods

### Materials

This study investigates the interaction between staff and patients. Three hundred and seventy interaction sequences were analysed.

### Staff

A random sample of 34 professional caretakers was recruited from a special unit at the Ullevål University Hospital. The amount of work experience among the caretakers varied and their different professional backgrounds comprised nurses (10%), nurse's aides (73%), and nonqualified staff (17%). Their work experience had a mean of 5.6 years (range: 10 months – 16 years). The staff had no knowledge of the observation categories prior to the observation period.

### Patients

A selected sample of 4 patients was recruited. Inclusion criteria were verified diagnoses of intellectual disability, autism and schizophrenia. The patients were mildly- severely intellectually disabled, between 31 and 52 years.

They showed social withdrawal and severely impaired global functioning. The patients' psychotic symptoms were measured previous to the video recording (14).

They were behaviourally disorganised and showed derailment, disorientation, aimlessness and problems of task sequencing. Three patients showed disorganised language. The four patients were not in the most acute phase during the video-recording period. They had been admitted to psychiatric hospitalisation for between one and twelve years.

### Measures and Procedure

Observation categories were designed according to available theory and research. Staff and patient measurements are presented and discussed in part one of this paper (14).

Staff and patients were observed via videotapes over a 9-month period and then scored by two independent observers.

Statistical analyses were computed by contingency tables. Statistical significance in contingency tables was computed by Chi-square.

The study was conducted in a special unit in a psychiatric hospital located in Oslo, Norway. This unit is concerned about the ward atmosphere, which is an important psychosocial factor for treating in-patients (15,16). The ward atmosphere, suitable for psychotic patients, ought to encompass these factors: few patients within each unit; a high degree of order, organisation, and program clarity; and a low degree of hostility, anger, and aggression (17). The special unit uses an evolved milieu therapy founded on user-involvement and patient autonomy principles over a 10-year period since 1990. During this period 95% the long-term patients had marked improved global functioning (13).

### Unit of Observation

Data are based on observation of behaviour sequences; i.e., turn-taking interactions between patients and caretakers (19,20). Observation of turn-taking is based on a coding system where all behaviours of interest for the actual study are systematically defined prior to the observation and scoring. A turn is defined by an act, verbal or non-verbal, or both in one act, exclusively performed by caretaker or patient. Examples of turns are asking a question, gaze initiative from the patient, pouring milk from the bottle, etc.

Statistical analysis of behavioural sequences is based on observational data, which are systematically scored and made into objects for lag-analysis, i.e. the observations are time-coded and therefore possible to be analysed when succeeded by specific behaviours closely in time and occurrence. Conditional associations can reflect probabilities of concurrence; e.g. what is the probability of organised behaviour in

**Table 1. Probability of disorganised and organised behaviour in patients responding to the effective and non-effective staff communication**

Patient	Staff	
	NEC	EC
Disorganised behaviour	44.8%	26.5%
Organised behaviour	55.2%	73.5%

NEC = non-effective communication; EC = effective communication. N = 2546 turns

\*Percentage of all staff/patient turns

the patient given effective communication *before* the patient displayed this behaviour?

Data are organised on two levels, episodes and turns. *Episodes* are defined by –«Start = interaction initiated either by patient or staff» and –«end = a natural end of an interaction sequence or a pause of interaction of a certain length» (different for each patient according to their average response time). The response time for the patients ranged from 3 to 6 seconds in length.

The total number of turns scored in episodes varied from 1 to 32 with a mean of 6.9 turns per episode. Suitable situations, in which probability of interaction was high, were chosen for this purpose; meals, dressing, school lessons, and social settings like coffee breaks. A total of 370 episodes were scored; 1169 caretaker turns and 1377 patient turns (2546).

Independent variables are staff communication. Effect variables are disorganised behaviour in patients. Initiatives from the patient are scored when present.

### Statistical analysis

The relationship between staff communication and patient behaviour were analysed by contingency table analyses for episodes and turns. Statistical significance in contingency tables was computed by Chi-square.

### Ethical considerations

Permission to conduct the present study has been given by the following instances: the director of the hospital and the four families/guardians have been informed, and they approved. All staff gave their informed consent. One patient gave informed consent. The three others are not capable of giving consent. They were informed prior to all video-recordings about the recording. The Eastern Regional Ethical Board of Norway has given permission to record patients and caretakers using a video camera. All original data (videotapes) will be destroyed when the study is closed, as required by Norwegian law.

**Table 2. Probability of disorganised and organised behaviour and initiatives in patients given main categories of effective and non-effective communication**

Staff communication	Patient Behaviour		
	Initiatives	Organised Behaviour	Disorganised Behaviour
Meaningful response	19.5%	30.1%	50.4%
Joint attention	9.0%	55.8%	35.2%
Task sustenance	1.3%	66.7%	32.0%
Emotional support	22.2%	55.6%	22.2%
Meaningless response	14.0%	18.6%	67.4%
No joint attention (Other focus)	5.7%	44.3%	50.0%

N = 2546 turns

**Table 3. Influence of patient behaviour on staff communication**

	Meaningful response	Attention sustenance	Task sustenance	Emotional support	Meaningless response	No joint attention
<b>Organised behaviour</b>	33.9%	33.0%	15.4%	0.9%	3.5%	13.2%
<b>Disorganised behaviour</b>	37.9%	28.2%	9.6%	2.5%	10.4%	11.4%
<b>Initiatives</b>	65.0%	16.9%	5.1%	0.6%	11.3%	1.1%

## Results

Table 1 shows the relationship between staff and patient turns. The conditional probability of organised behaviour demonstrated by the patient, which is contingent on effective communication by the staff, is 0.74. In comparison, a conditional probability of 0.55 was found when staff provided non-effective communication. The correlation between staff behaviour and patient behaviour was clearly statistically significant ( $\chi^2=18.2$ ,  $df=1$ ,  $p<.0001$ ).

Table 2 shows, for each main category of staff communication, the conditional probability of organised behaviour, disorganised behaviour, and initiatives in the patient when the staff performs effective communication and non-effective communication.

When the presence or non-presence of effective communication are conditions, effective communication seem related to both organised behaviour and initiatives in the patients. The conditional probability of organised behaviour considerably increases and the probability of initiatives from the patient also increases when the communication between caretaker and patient become meaningful. The conditional probability of organised behaviour and initiatives in the patient when the staff provide a *meaningful response* is high. The conditional probability of organised behaviour is especially high when the staff master *attention sustenance*, *task sustenance*, or *emotional support*. It is most likely that the patient demonstrates initiative when the staff provide *emotional support*.

A reverse pattern with fewer initiatives and a higher probability of disorganised behaviour is displayed when the staff's communication is meaningless. *Meaningless response* encourages fewer patient initiatives and more disorganised behaviour. *No joint attention* encourages fewer initiatives and much more disorganised behaviour.

Table 3 presents the conditional probability of *meaningful response*, *attention sustenance*, *task sustenance*, *emotional support*, *meaningless response*, and *no joint attention*, given organised behaviour, disorganised behaviour, and initiatives in the patient. Note that the probability of *meaningful response* is 65% given an initiative from a patient.

Table 4 demonstrates whether the correlation in staff communication is contingent upon the

patient's organised or disorganised behaviour and initiatives. Skills on episode level are not correlated with patient behaviour, although patient behaviour is not scored on episode level.

The most significant categories in Table 4 are *meaningful answer*, *meaningless answer*, *directive given inside patient's attention area*, *initiatives outside attention area*, *task support*, and *physical soothing*. The rest of the categories are either scored as infrequent or do not correlate with patient behaviour. Categories scored on episode level cannot be examined by statistical methods because all patient behaviours are scored on turn-level.

## Work Experience

The sample of 34 staff members' work experience was divided into three groups: less than 1 year experience on the Special Unit for adults with Intellectual Disability and Psychiatric Disorders; from 1 to 5 years experience; and more than 5 years experience. The model for categorising work experience is based on Benner's clinical practice theory: *From Novice to Expert, Acquiring Skills* (21).

The results indicate that the most experienced staff, with more than 5 years experience with this group of patients, most often performed effective communication. The staff with less than 1 year most often provide non-effective communication, especially *do not give response* and *reject choice*. These categories are used infrequently in the total sample, but were used more by the less experienced staff.

## Discussion

The impact of effective communication in the present sample is considerable. The effects that relate to behaviour and initiatives seem to be connected and positively influenced by meaningful communica-

**Table 4. Effects of the separate skills related to disorganised behaviour and initiatives**

Main categories		Subcategories	Organised behaviour	Disorganised behaviour	Initiatives
Response	Meaningful response	Meaningful answer	0.18 **	0.10 **	0.29 **
		Confirm choice	—	—	—
	Meaningless response	No response	0.03	0.00	0.02
		Meaningless answer	– 0.16 **	0.13 **	0.11 **
		Reject choice	– 0.04	0.04	0.02
Attention	Joint attention	Attention-directed initiative	0.08 *	– 0.06 *	– 0.09 *
		Attention-directed directive	0.16 **	– 0.11 **	– 0.15 **
	Other focus	Outside att. area-initiatives	– 0.02	0.05	– 0.10**
		Outside att. area-directive	0.04	– 0.03	– 0.06
		Lost attention	– 0.07	0.08 *	– 0.04
Task sustenance	Task sustenance	Physical limitation	0.04	0.01	– 0.07
		Task support	0.14 **	– 0.11 **	– 0.11 **
Emotional support	Emotional support	Confirms feeling	0.01	– 0.04	0.00
		Physical soothing	0.07 *	0.11 **	0.07 *
		Mirroring	—	—	—

\*Significance level,  $p<0.05$ ; \*\*significance level,  $p<0.01$ ; – = not frequent enough for correlations.

N = 1169 staff turns and 1377 patient turns

tion; more patient initiatives can be explained by more organised behaviour.

An unexpected finding is that effective communication (EC) affects a patient's activity level, i.e., how often the patient performs organised behaviour or initiatives. This is surprisingly because these patients are known to be passive due to autism and psychotic cognitive disorganisation. EC has a particular effect on instigating initiatives, which is regarded as especially impaired in these patients.

Effective communication counteracts disorganised behaviour – a high level of disorganised behaviour in this sample of intellectual disabled adults with severe psychotic cognitive disorganisation would be expected to be frequently occurring. However, when the staff performs non-effective communication (NEC), the amount of disorganised behaviour increases. This is shown by the negative correlations between NEC subcategories and disorganised behaviour (Table 4).

To be able to continue with and remain concentrated within the limitations of a certain activity, or to perform a certain task, is particularly influenced by effective communication. The result of this relationship is probably the combination of effective communication and a highly structured interaction situation, such as activities that are structured and proceedings that are known by the patient. When the patient appears to be continuously active, this is in fact a testament to well-planned and highly structured tasks that make the patient focus on certain objects and the communication partner, who attends to the patient's autism and psychotic disorganisation.

Effective communication seems to be an integrated way to interact with the patient and the effects differ between the four main categories. *Responding meaningfully* seems to encourage initiatives in the patients, but has the least impact on disorganised behaviour. *Attention sustenance* has a positive effect on disorganisation. The results confirm the importance of adjusting to the patient as the communication partner seeks the patient's attention area to achieve contact so the patient focuses on objects or persons.

*Task sustenance* has the most prominent effect on disorganised behaviour in this sample. When task sustenance is used to help a strongly confused patient who cannot perform the ongoing task, he may become less frustrated and will experience the staff as both an emotional and practical support. *Task sustenance* helps the patient to master the ongoing task, which leads to fewer initiatives.

*Emotional support* also seems to have strong effects on disorganised behaviour. When the staff provides emotional support, the chance of organised behaviour in the patient is approximately 3:1.

Effective communication is demonstrated by short-term positive impact, yet, no long-term effects can be achieved without a short-term effects (22). The strong relation between staff communication and subsequent patient behaviour might indicate a causal connection between staff and patient behaviour in this sample; however, causality cannot be explained with the results from only one study. Yet, the four categories of effective communication are respectively known by previous reports to have positive impact on the mental state of persons with emotional problems, which supports the hypothesis of a causal connection.

Staff behaviour is less influenced by patient behaviour than vice versa. It is conceivable that the staff members are not too influenced by psychotic patient behaviour. Research in acute psychiatric wards indicates that a mature staff milieu contain psychotic behaviour better than an immature milieu (23).

The field in which the empirical data were collected is influenced by psychodynamic psychiatry (14). Some of the findings were some unexpected and might draw attention to topics particularly interesting for educational purposes. The staff do not often *confirm choices* acted by patients. Making choices for the single patient ought to be a highly attended topic for disability staff working in a field where giving directives and planning the day for the patients traditionally have been leading principles (24). *Physical soothing* is used occasionally, but not often. This might be a result of the actual group of staff members' knowledge of difficulties that autistic persons may experience with physical touch (25).

Staff with more work experience in the present sample seem to

communicate effectively more often. This is an expected result. The fact that 5 years of experience is needed to communicate predominantly effectively supports the idea that communication skills should be an essential part of education programmes, especially for 'novices'. Research on communication skills in specialised fields of oncology and geriatric nursing indicate that communication skills are improved through training and counselling.

## Conclusion

Communication skills of intellectual disability staff can be monitored and evaluated.

Communication strategies that are considered effective seem to decrease disorganised symptoms in intellectual disabled adults, and increase the amounts of initiatives from the patients.

More experienced professional staff communicate effectively more often.

The present study has a potential for improvement of counselling of intellectual disability nurses

Accepted for publication 15.10.2007

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